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ABSTRACT

This first Report of the Surgeon General on Mental Health represents the initial step in advancing the notion that mental health is fundamental to general health. It states that a review of research on mental health revealed two findings. First, the efficacy of treatment is well documented, and second, a range of treatment exists for most mental disorders. The report provides the opportunity to dispel the myths and stigma surrounding mental illness. It encourages individuals to seek treatment when they find themselves experiencing signs and symptoms of mental distress. Chapter 1 elaborates on the themes of the report and describes criteria applied to the scientific evidence cited. Chapter 2 was written to provide background information to help persons from outside the health field better understand the topics. Chapter 3 details normal development, provides overview of risk factors and prevention, and provides overview of mental disorders in children. Chapter 4 reviews the current state of knowledge about mental health in adults, along with selected disorders. Chapter 5 reviews normal developmental milestones of aging and then considers mental disorders in older people. Chapter 6 examines what recent research has revealed about the organizing and financing of mental health services, as well as cost and quality of those services. Chapter 7 discusses the values underlying confidentiality, its importance in individual decisions to seek mental health treatment, and the legal framework governing confidentiality and potential problems with this framework. Chapter 8 reiterates the need to establish mental health as a cornerstone of general health, to place mental health treatment in the mainstream of health care services, and to ensure access to care. (Contains over 300 references, 31 tables, and 22 figures.) (JDM)

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ED 441 209

Mental Health

A Report of the Surgeon General

Executive Summary

DEPARTMENT OF HEALTH AND HUMAN SERVICES
U.S. Public Health Service

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
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The Center for Mental Health Services

Substance Abuse and Mental Health Services Administration

NIMH

National Institute
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Message from Donna E. Shalala

Secretary of Health and Human Services

The United States leads the world in understanding the importance of overall health and well-being to the strength of a Nation and its people. What we are coming to realize is that mental health is absolutely essential to achieving prosperity. According to the landmark "Global Burden of Disease" study, commissioned by the World Health Organization and the World Bank, 4 of the 10 leading causes of disability for persons age 5 and older are mental disorders. Among developed nations, including the United States, major depression is the leading cause of disability. Also near the top of these rankings are manic-depressive illness, schizophrenia, and obsessive-compulsive disorder. Mental disorders also are tragic contributors to mortality, with suicide perennially representing one of the leading preventable causes of death in the United States and worldwide.

The U.S. Congress declared the 1990s the Decade of the Brain. In this decade we have learned much through research—in basic neuroscience, behavioral science, and genetics—about the complex workings of the brain. Research can help us gain a further understanding of the fundamental mechanisms underlying thought, emotion, and behavior—and an understanding of what goes wrong in the brain in mental illness. It can also lead to better treatments and improved services for our diverse population.

Now, with the publication of this first Surgeon General's Report on Mental Health, we are poised to take what we know and to advance the state of mental health in the Nation. We can with great confidence encourage individuals to seek treatment when they find themselves experiencing the signs and symptoms of mental distress. Research has given us effective treatments and service delivery strategies for many mental disorders. An array of safe and potent medications and psychosocial interventions, typically used in combination, allow us to effectively treat most mental disorders.

This seminal report provides us with an opportunity to dispel the myths and stigma surrounding mental illness. For too long the fear of mental illness has been profoundly destructive to people's lives. In fact mental illnesses are just as real as other illnesses, and they are like other illnesses in most ways. Yet fear and stigma persist, resulting in lost opportunities for individuals to seek treatment and improve or recover.

In this Administration, a persistent, courageous advocate of affordable, quality mental health services for all Americans is Mrs. Tipper Gore, wife of the Vice President. We salute her for her historic leadership and for her enthusiastic support of the initiative by the Surgeon General, Dr. David Satcher, to issue this groundbreaking Report on Mental Health.

The 1999 White House Conference on Mental Health called for a national antistigma campaign. The Surgeon General issued a Call to Action on Suicide Prevention in 1999 as well. This Surgeon General's Report on Mental Health takes the next step in advancing the important notion that mental health is fundamental health.

Foreword

Since the turn of this century, thanks in large measure to research-based public health innovations, the lifespan of the average American has nearly doubled. Today, our Nation's physical health—as a whole—has never been better. Moreover, illnesses of the body, once shrouded in fear—such as cancer, epilepsy, and HIV/AIDS to name just a few—increasingly are seen as treatable, survivable, even curable ailments. Yet, despite unprecedented knowledge gained in just the past three decades about the brain and human behavior, mental health is often an afterthought and illnesses of the mind remain shrouded in fear and misunderstanding.

This Report of the Surgeon General on Mental Health is the product of an invigorating collaboration between two Federal agencies. The Substance Abuse and Mental Health Services Administration (SAMHSA), which provides national leadership and funding to the states and many professional and citizen organizations that are striving to improve the availability, accessibility, and quality of mental health services, was assigned lead responsibility for coordinating the development of the report. The National Institutes of Health (NIH), which supports and conducts research on mental illness and mental health through its National Institute of Mental Health (NIMH), was pleased to be a partner in this effort. The agencies we respectively head were able to rely on the enthusiastic participation of hundreds of people who played a role in researching, writing, reviewing, and disseminating this report. We wish to express our appreciation and that of a mental health constituency, millions of Americans strong, to Surgeon General David Satcher, M.D., Ph.D., for inviting us to participate in this landmark report.

The year 1999 witnessed the first White House Conference on Mental Health and the first Secretarial Initiative on Mental Health prepared under the aegis of the Department of Health and Human Services. These activities set an optimistic tone for progress that will be realized in the years ahead. Looking ahead, we take special pride in the remarkable record of accomplishment, in the spheres of both science and services, to which our agencies have contributed over past decades. With the impetus that the Surgeon General's report provides, we intend to expand that record of accomplishment. This report recognizes the inextricably intertwined relationship between our mental health and our physical health and well-being. The report emphasizes that mental health and mental illnesses are important concerns at all ages. Accordingly, we will continue to attend to needs that occur across the lifespan, from the youngest child to the oldest among us.

The report lays down a challenge to the Nation—to our communities, our health and social service agencies, our policymakers, employers, and citizens—to take action. SAMHSA and NIH look forward to continuing our collaboration to generate needed knowledge about the brain and behavior and to translate that knowledge to the service systems, providers, and citizens.

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Preface

from the Surgeon General
U.S. Public Health Service

The past century has witnessed extraordinary progress in our improvement of the public health through medical science and ambitious, often innovative, approaches to health care services. Previous Surgeons General reports have saluted our gains while continuing to set ever higher benchmarks for the public health. Through much of this era of great challenge and greater achievement, however, concerns regarding mental illness and mental health too often were relegated to the rear of our national consciousness. Tragic and devastating disorders such as schizophrenia, depression and bipolar disorder, Alzheimer's disease, the mental and behavioral disorders suffered by children, and a range of other mental disorders affect nearly one in five Americans in any year, yet continue too frequently to be spoken of in whispers and shame. Fortunately, leaders in the mental health field—fiercely dedicated advocates, scientists, government officials, and consumers—have been insistent that mental health flow in the mainstream of health. I agree and issue this report in that spirit.

This report makes evident that the neuroscience of mental health—a term that encompasses studies extending from molecular events to psychological, behavioral, and societal phenomena—has emerged as one of the most exciting arenas of scientific activity and human inquiry. We recognize that the brain is the integrator of thought, emotion, behavior, and health. Indeed, one of the foremost contributions of contemporary mental health research is the extent to which it has mended the destructive split between "mental" and "physical" health.

We know more today about how to treat mental illness effectively and appropriately than we know with certainty about how to prevent mental illness and promote mental health. Common sense and respect for our fellow humans tells us that a focus on the positive aspects of mental health demands our immediate attention.

Even more than other areas of health and medicine, the mental health field is plagued by disparities in the availability of and access to its services. These disparities are viewed readily through the lenses of racial and cultural diversity, age, and gender. A key disparity often hinges on a person's financial status; formidable financial barriers block off needed mental health care from too many people regardless of whether one has health insurance with inadequate mental health benefits, or is one of the 44 million Americans who lack any insurance. We have allowed stigma and a now unwarranted sense of hopelessness about the opportunities for recovery from mental illness to erect these barriers. It is time to take them down.

Promoting mental health for all Americans will require scientific know-how but, even more importantly, a societal resolve that we will make the needed investment. The investment does not call for massive budgets; rather, it calls for the willingness of each of us to educate ourselves and others about mental health and mental illness, and thus to confront the attitudes, fear, and misunderstanding that remain as barriers before us. It is my intent that this report will usher in a healthy era of mind and body for the Nation.

David Satcher, M.D., Ph.D.
Surgeon General

EXECUTIVE SUMMARY

A REPORT OF THE SURGEON GENERAL ON MENTAL HEALTH

***Mental health**—the successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity; from early childhood until late life, mental health is the springboard of thinking and communication skills, learning, emotional growth, resilience, and self-esteem.*

***Mental illness**—the term that refers collectively to all mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning.*

This is the first Surgeon General's report ever issued on the topic of mental health and mental illness. The science-based report conveys several messages. One is that **mental health is fundamental to health**. The qualities of mental health are essential to leading a healthy life. Americans assign high priority to preventing disease and promoting personal well-being and public health; so too must we assign priority to the task of promoting mental health and preventing mental disorders. Nonetheless, mental disorders occur and, thus, treatment and mental health services are critical to the Nation's health. These emphases, combined with research to increase the knowledge needed to treat and prevent mental and behavioral disorders, constitute a broad public health approach to an urgent health concern.

A second message of the report is that **mental disorders are real health conditions** that have an immense impact on individuals and families throughout this Nation and the world. Appreciation of the clinically and economically devastating nature of mental disorders is part of a quiet scientific revolution that not only has documented the extent of the problem, but in recent years has generated many real solutions. The decision to publish the report at this time was based, in part, on the tremendous growth of the science base that is enriching our understanding of the awe-inspiring complexity of the brain and behavior. This understanding increasingly supports mental health practices.

The body of this report is a summary of an extensive review of the scientific literature and of consultations with mental health care providers and consumers. Contributors guided by the Office of the Surgeon General examined more than 3,000 research articles and other materials, including first-person accounts from individuals who have experienced mental disorders. Today, a strong consensus among Americans in all walks of life holds that our society no longer can afford to view mental health as separate and unequal to general health. This consensus resonates with the Surgeon General's conviction that mental health should be part of the mainstream of health.

The review of research supports two main findings:

- **The efficacy of mental health treatments is well documented,** and
- **A range of treatments exists for most mental disorders.**

On the strength of these findings, the single, explicit recommendation of the report is to ***seek help if you have a mental health problem or think you have symptoms of a mental disorder*.**

Once a person has made the decision to seek help for a mental health problem, he or she can choose from a broad variety of helping sources, treatment approaches, and service settings. There is no "one size fits all" treatment for mental disorders. Personal preference may influence, for example, the choice of psychotherapeutic, or "talk," therapy over the use of medications; in another case, an individual may feel most comfortable raising questions about symptoms of mental distress with a family doctor, with a trusted member of the clergy, or, if a child's health is the subject of concern, with a teacher or a school counselor. There are many individuals who are familiar with questions about mental health care and who, as a first point of contact, can provide invaluable assistance in obtaining appropriate and effective care.

Despite the efficacy of treatment options and the many possible ways of obtaining a treatment of choice, nearly half of all Americans who have a severe mental illness do not seek treatment. Most often, reluctance to seek care is an unfortunate outcome of very real barriers. Foremost among these is the stigma that many in our society attach to mental illness and to people who have a mental illness.

Stigma erodes confidence that mental disorders are valid, treatable health conditions. It leads people to avoid socializing, employing or working with, or renting to or living near persons who have a mental disorder, especially a severe disorder like schizophrenia. Stigma deters the public from wanting to pay for care and, thus, reduces consumers' access to resources and opportunities for treatment and social services. A consequent inability or failure to obtain treatment reinforces destructive patterns of low self-esteem, isolation, and hopelessness. Stigma tragically deprives people of their dignity and interferes with their full participation in society. It must be overcome.

Increasingly effective treatments for mental disorders promise to be the most effective antidote to stigma. Effective interventions help people to understand that mental disorders are not character flaws but are legitimate illnesses that respond to specific treatments, just as other health conditions respond to medical interventions. Fresh approaches to disseminating research information are needed urgently. While they are being developed, this report provides information that organizations, experts, and many other individuals can use to educate all Americans about mental health and mental illness.

Overarching Themes of the Surgeon General's Report

Key themes, summarized here, run throughout the report. The importance of information, policies, and actions that will reduce and eventually eliminate the cruel and unfair stigma attached to mental illness is one. The importance of a solid research base for every mental health and mental illness intervention is another. As our Nation has seen in the past, establishing mental health policy on the basis of good intentions alone can make bad situations worse; evaluating the practicality and effectiveness of new approaches is efficient and, more critically, is accountable to those for whom an intervention is intended. Additional themes of the report include the following.

Public Health Perspective

In the United States, mental health programs, like general health programs, are rooted in a *population-based public health model*. Broader in focus than medical models that concentrate on diagnosis and treatment, public health attends, in addition, to the health of a population in its entirety. A public health approach encompasses a focus on epidemiologic surveillance, health promotion, disease prevention, and access to services. Although much more is known through research about mental illness than about mental health, the report attaches high importance to public health practices that seek to identify risk factors for mental health problems; to mount preventive interventions that may block the emergence of severe illnesses; and to actively promote good mental health.

Mental Disorders Are Disabling

The World Health Organization, in collaboration with the World Bank and Harvard University, mounted an ambitious research effort in the mid-1990s to determine the "burden of disability" associated with the whole range of diseases and health conditions suffered by peoples throughout the world. Possibly the most striking finding of the landmark Global Burden of Disease study is that the impact of mental illness on overall health and productivity in the United States and throughout the world is profoundly underrecognized. Today, in established market economies such as the United States, mental illness is the second leading cause of disability and premature mortality. Mental disorders collectively account for more than 15 percent of the overall burden of disease from *all* causes and slightly more than the burden associated with all forms of cancer (Table 1). These data underscore the importance and urgency of treating and preventing mental disorders and of promoting mental health in our society.

Table 1. Disease burden by selected illness categories in established market economies, 1990

	Percent of Total DALYs*
All cardiovascular conditions	18.6
All mental illness**	15.4
All malignant disease (cancer)	15.0
All respiratory conditions	4.8
All alcohol use	4.7
All infectious and parasitic disease	2.8
All drug use	1.5

*Disability-adjusted life year (DALY) is a measure that expresses years of life lost to premature death and years lived with a disability of specified severity and duration (Murray & Lopez, 1996).

**Disease burden associated with "mental illness" includes suicide.

Mental Health and Mental Illness: Points on a Continuum

As will be evident in the pages that follow, "mental health" and "mental illness" may be thought of as points on a continuum. *Mental health* refers to the successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity. Mental health is indispensable to personal well-being, family and interpersonal relationships, and contribution to community or society. It is easy to overlook the value of mental health until problems surface. Yet from early childhood until death, mental health is the springboard of thinking and communication skills, learning, emotional growth, resilience, and self-esteem. These are the ingredients of each individual's successful contribution to community and society. Americans are inundated with messages about *success*—in school, in a profession, in parenting, in relationships—without appreciating that successful performance rests on a foundation of mental health.

Many ingredients of mental health may be identifiable, but mental health is not easy to define. In the words of a distinguished leader in the field of mental health prevention, ". . . built into any definition of wellness . . . are overt and covert expressions of values. Because values differ across cultures as well as among subgroups (and indeed individuals) within a culture, the ideal of a uniformly acceptable definition of the construct is illusory. . ." (Cowen, 1994). In other words, what it means to be mentally healthy is subject to many different interpretations that are rooted in value judgments that may vary across cultures. The challenge of defining mental health has stalled the development of programs to foster mental health (Secker, 1998), although some strides have been made—for example, wellness programs for older people.

Mental illness refers collectively to all diagnosable mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning. Alzheimer's disease exemplifies a mental disorder largely marked by alterations in thinking (especially forgetting). Depression exemplifies a mental disorder largely marked by alterations in mood. Attention-deficit/hyperactivity disorder exemplifies a mental disorder largely marked by alterations in behavior (overactivity) and/or thinking (inability to concentrate). Alterations in thinking, mood, or behavior spawn a host of problems—patient distress, impaired functioning, or heightened risk of death, pain, disability, or loss of freedom (DSM-IV, 1994).

This report uses the term "mental health problems" for signs and symptoms of insufficient intensity or duration to meet the criteria for any mental disorder. Almost everyone has experienced mental health problems in which the distress one feels matches some of the signs and symptoms of mental disorders. Mental health problems may warrant active efforts in health promotion, prevention, and treatment. Bereavement symptoms in older adults offer a case in point. Bereavement symptoms of less than 2 months' duration do not qualify as a mental disorder, according to professional manuals for diagnosis (DSM-IV, 1994). Nevertheless, bereavement symptoms can be debilitating if they are left unattended. They place older people at risk for depression, which, in turn, is linked to death from suicide, heart attack, or other causes (Zisook & Shuchter, 1991, 1993; Frasure-Smith et al., 1993, 1995; Conwell, 1996). Much can be done—through formal treatment or through support group participation—to ameliorate the symptoms and to avert the consequences of bereavement. In this case, early intervention is needed to address a mental health problem before it becomes a disorder.

Mind and Body Are Inseparable

As it examines mental health and illness in the United States, the report confronts a profound obstacle to public understanding, one that stems from an artificial, centuries-old separation of mind and body.

Even today, everyday language encourages a misperception that mental health or mental illness is unrelated to physical health or physical illness. In fact, the two are inseparable. In keeping with modern scientific thinking, this report uses mind to refer to all mental functions related to thinking, mood, and purposive behavior. The mind is generally seen as deriving from activities within the brain. Research reviewed for this report makes it clear that mental functions are carried out by a particular organ, the brain. Indeed, new and emerging technologies are making it increasingly possible for researchers to demonstrate the extent to which mental disorders and their treatment—both with medication and with psychotherapy—are reflected in physical changes in the brain.

Scope of the Report and General Conclusions

Chapter 1: Introduction and Themes

Chapter 1 of the report elaborates on the overarching themes highlighted above and describes the criteria applied to the scientific evidence that is cited throughout the report. The chapter also lists the key conclusions drawn from each succeeding chapter. These conclusions are provided, as well, in the following pages of this Executive Summary.

Chapter 2: The Fundamentals of Mental Health and Mental Illness

The past 25 years have been marked by several discrete, defining trends in the mental health field. These have included:

- The extraordinary pace and productivity of scientific research on the brain and behavior;
- The introduction of a range of effective treatments for most mental disorders;
- A dramatic transformation of our society's approaches to the organization and financing of mental health care; and
- The emergence of powerful consumer and family movements.

Scientific Research. The brain has emerged as the central focus for studies of mental health and mental illness. New scientific disciplines, technologies, and insights have begun to weave a seamless picture of the way in which the brain mediates the influence of biological, psychological, and social factors on human thought, behavior, and emotion in health and in illness. Molecular and cellular biology and molecular genetics, which are complemented by sophisticated cognitive and behavioral science, are preeminent research disciplines in the contemporary neuroscience of mental health. These disciplines are affording unprecedented opportunities for "bottom-up" studies of the brain. This term refers to research that is examining the workings of the brain at the most fundamental levels. Studies focus, for example, on the complex neurochemical activity that occurs within individual nerve cells, or neurons, to process information; on the properties and roles of proteins that are expressed, or produced, by a person's genes; and on the interaction of genes with diverse environmental influences. All of these activities now are understood, with increasing clarity, to underlie learning, memory, the experience of emotion, and, when these processes go awry, the occurrence of mental illness or a mental health problem.

Equally important to the mental health field is "top-down" research; here, as the term suggests, the aim is to understand the broader behavioral context of the brain's cellular and molecular activity and to learn how individual neurons work together in well-delineated neural circuits to perform mental functions.

Effective Treatments. As information accumulates about the basic workings of the brain, it is the task of translational research to transfer new knowledge into clinically relevant questions and targets of research opportunity—to discover, for example, what specific properties of a neural circuit might make it receptive to safer, more effective medications. To elaborate on this example, theories derived from knowledge about basic brain mechanisms are being wedded more closely to brain imaging tools such as functional Magnetic Resonance Imaging (MRI) that can observe actual brain activity. Such a collaboration would permit investigators to monitor the specific protein molecules intended as the "targets" of a new medication to treat a mental illness or, indeed, to determine how to optimize the effect on the brain of the learning achieved through psychotherapy.

In its entirety, the new "integrative neuroscience" of mental health offers a way to circumvent the antiquated split between the mind and the body that historically has hampered mental health research. It also makes it possible to examine scientifically many of the important psychological and behavioral theories regarding normal development and mental illness that have been developed in years past. The unswerving goal of mental health research is to develop and refine clinical treatments as well as preventive interventions that are based on an understanding of specific mechanisms that can contribute to or lead to illness but also can protect and enhance mental health.

Mental health clinical research encompasses studies that involve human participants, conducted, for example, to test the efficacy of a new treatment. A noteworthy feature of contemporary clinical research is the new emphasis being placed on studying the effectiveness of interventions in actual practice settings. Information obtained from such studies increasingly provides the foundation for services research concerned with the cost, cost-effectiveness, and "deliverability" of interventions and the design—including economic considerations—of service delivery systems.

Organization and Financing of Mental Health Care. Another of the defining trends has been the transformation of the mental illness treatment and mental health services landscapes, including increased reliance on primary health care and other human service providers. Today, the U.S. mental health system is multifaceted and complex, comprising the public and private sectors, general health and specialty mental health providers, and social services, housing, criminal justice, and educational agencies. These agencies do not always function in a coordinated manner. The configuration of the system reflects necessary responses to a broad array of factors including reform movements, financial incentives based on who pays for what kind of services, and advances in care and treatment technology. Although the hybrid system that exists today serves diverse functions well for many people, individuals with the most complex needs and the fewest financial resources often find the system fragmented and difficult to use. A challenge for the Nation in the near-term future is to speed the transfer of new evidence-based treatments and prevention interventions into diverse service delivery settings and systems, while ensuring greater coordination among these settings and systems.

Consumer and Family Movements. The emergence of vital consumer and family movements promises to shape the direction and complexion of mental health programs for many years to come. Although divergent in their historical origins and philosophy, organizations representing consumers and family members have promoted important, often overlapping, goals and have invigorated the fields of research as well as treatment and service delivery design. Among the principal goals shared by much of the consumer movement are to overcome stigma and prevent discrimination in policies affecting persons with mental illness; to encourage self-help and a focus on recovery from mental illness; and to draw attention to the special needs associated with a particular disorder or disability as well as with age or gender or by the racial and cultural identity of those who have mental illness.

Chapter 2 of the report was written to provide background information that would help persons from outside the mental health field better understand topics addressed in subsequent chapters of the report. Although the chapter is meant to serve as a mental health primer, its depth of discussion supports a range of conclusions:

- The multifaceted complexity of the brain is fully consistent with the fact that it supports all behavior and mental life. Proceeding from an acknowledgment that all psychological experiences are recorded ultimately in the brain and that all psychological phenomena reflect biological processes, the modern neuroscience of mental health offers an enriched understanding of the inseparability of human experience, brain, and mind.
- Mental functions, which are disturbed in mental disorders, are mediated by the brain. In the process of transforming human experience into physical events, the brain undergoes changes in its cellular structure and function.
- Few lesions or physiologic abnormalities define the mental disorders, and for the most part their causes remain unknown. Mental disorders, instead, are defined by signs, symptoms, and functional impairments.
- Diagnoses of mental disorders made using specific criteria are as reliable as those for general medical disorders.
- About one in five Americans experiences a mental disorder in the course of a year. Approximately 15 percent of all adults who have a mental disorder in one year also experience a co-occurring substance (alcohol or other drug) use disorder, which complicates treatment.
- A range of treatments of well-documented efficacy exists for most mental disorders. Two broad types of intervention include psychosocial treatments—for example, psychotherapy or counseling—and psychopharmacologic treatments; these often are most effective when combined.
- In the mental health field, progress in developing preventive interventions has been slow because, for most major mental disorders, there is insufficient understanding about etiology (or causes of illness) and/or there is an inability to alter the *known* etiology of a particular disorder. Still, some successful strategies have emerged in the absence of a full understanding of etiology.
- About 10 percent of the U.S. adult population use mental health services in the health sector in any year, with another 5 percent seeking such services from social service agencies, schools, or religious or self-help groups. Yet critical gaps exist between those who need service and those who receive service.
- Gaps also exist between optimally effective treatment and what many individuals receive in actual practice settings.
- Mental illness and less severe mental health problems must be understood in a social and cultural context, and mental health services must be designed and delivered in a manner that is sensitive to the perspectives and needs of racial and ethnic minorities.
- The consumer movement has increased the involvement of individuals with mental disorders and their families in mutual support services, consumer-run services, and advocacy. They are powerful agents for changes in service programs and policy.
- The notion of recovery reflects renewed optimism about the outcomes of mental illness, including that achieved through an individual's own self-care

efforts, and the opportunities open to persons with mental illness to participate to the full extent of their interests in the community of their choice.

Mental Health and Mental Illness Across the Lifespan

The Surgeon General's report takes a lifespan approach to its consideration of mental health and mental illness. Three chapters that address, respectively, the periods of childhood and adolescence, adulthood, and later adult life beginning somewhere between ages 55 and 65, capture the contributions of research to the breadth, depth, and vibrancy that characterize all facets of the contemporary mental health field.

The disorders featured in depth in Chapters 3, 4, and 5 were selected on the basis of the frequency with which they occur in our society, and the clinical, societal, and economic burden associated with each. To the extent that data permit, the report takes note of how gender and culture, in addition to age, influence the diagnosis, course, and treatment of mental illness. The chapters also note the changing role of consumers and families, with attention to informal support services (i.e., unpaid services), with which many consumers are comfortable and upon which they depend for information. Persons with mental illness and, often, their families welcome a proliferating array of support services—such as self-help programs, family self-help, crisis services, and advocacy—that help them cope with the isolation, family disruption, and possible loss of employment and housing that may accompany mental disorders. Support services can help to dissipate stigma and to guide patients into formal care as well.

Mental health and mental illness are dynamic, ever-changing phenomena. At any given moment, a person's mental status reflects the sum total of that individual's genetic inheritance and life experiences. The brain interacts with and responds—both in its function and in its very structure—to multiple influences continuously, across every stage of life. At different stages, variability in expression of mental health and mental illness can be very subtle or very pronounced. As an example, the symptoms of separation anxiety are normal in early childhood but are signs of distress in later childhood and beyond. It is all too common for people to appreciate the impact of developmental processes in children, yet not to extend that conceptual understanding to older people. In fact, people continue to develop and change throughout life. Different stages of life are associated with vulnerability to distinct forms of mental and behavioral disorders but also with distinctive capacities for mental health.

Even more than is true for adults, children must be seen in the context of their social environments—that is, family and peer group, as well as that of their larger physical and cultural surroundings. Childhood mental health is expressed in this context, as children proceed along the arc of development. A great deal of contemporary research focuses on developmental processes, with the aim of understanding and predicting the forces that will keep children and adolescents mentally healthy and maintain them on course to become mentally healthy adults. Research also focuses on identifying what factors place some at risk for mental illness and, yet again, what protects some children but not others despite exposure to the *same* risk factors. In addition to studies of normal development and of risk factors, much research focuses on mental disorders in childhood and adolescence and what can be done to prevent or treat these conditions and on the design and operation of service settings best suited to the needs of children.

For about one in five Americans, adulthood—a time for achieving productive vocations and for sustaining close relationships at home and in the community—is interrupted by mental illness. Understanding why and how mental disorders occur in adulthood, often with no apparent portents of illness in earlier years, draws heavily on the full panoply of research conducted under the aegis of the mental health field. In years past, the onset, or occurrence, of mental illness in the adult years was attributed principally to observable phenomena—for example, the burden of stresses associated with career or family, or the inheritance of a disease viewed to run in a particular family. Such explanations now may appear naive at best. Contemporary studies of the brain and behavior are racing to fill in the picture by elucidating specific neurobiological and genetic mechanisms that are the platform upon which a person's life experiences can either strengthen mental health or lead to mental illness. It now is recognized that factors that influence brain development prenatally may set the stage for a vulnerability to illness that may lie dormant throughout childhood and adolescence. Similarly, no single gene has been found to be responsible for any specific mental disorder; rather, variations in multiple genes contribute to a disruption in healthy brain function that, under certain environmental conditions, results in a mental illness. Moreover, it is now recognized that socioeconomic factors affect individuals' vulnerability to mental illness and mental health problems. Certain demographic and economic groups are more likely than others to experience mental health problems and some mental disorders. Vulnerability alone may not be sufficient to cause a mental disorder; rather, the causes of most mental disorders lie in some combination of genetic and environmental factors, which may be biological or psychosocial.

The fact that many, if not most, people have experienced mental health problems that mimic or even match some of the symptoms of a diagnosable mental disorder tends, ironically, to prompt many people to underestimate the painful, disabling nature of severe mental illness. In fact, schizophrenia, mood disorders such as major depression and bipolar illness, and anxiety often are devastating conditions. Yet relatively few mental illnesses have an unremitting course marked by the most acute manifestations of illness; rather, for reasons that are not yet understood, the symptoms associated with mental illness tend to wax and wane. These patterns pose special challenges to the implementation of treatment plans and the design of service systems that are optimally responsive to an individual's needs during every phase of illness. As this report concludes, enormous strides are being made in diagnosis, treatment, and service delivery, placing the productive and creative possibilities of adulthood within the reach of persons who are encumbered by mental disorders.

Late adulthood is when changes in health status may become more noticeable and the ability to compensate for decrements may become limited. As the brain ages, a person's capacity for certain mental tasks tends to diminish, even as changes in other mental activities prove to be positive and rewarding. Well into late life, the ability to solve novel problems can be enhanced through training in cognitive skills and problem-solving strategies.

The promise of research on mental health promotion notwithstanding, a substantial minority of older people are disabled, often severely, by mental disorders including Alzheimer's disease, major depression, substance abuse, anxiety, and other conditions. In the United States today, the highest rate of suicide—an all-too-common consequence of unrecognized or inappropriately treated depression—is found in older males. This fact underscores the urgency of ensuring that health care provider training properly emphasizes skills required to differentiate accurately the causes of cognitive, emotional, and behavioral symptoms that may, in some instances, rise to the level of mental disorders, and in other instances be expressions of unmet general medical needs.

As the life expectancy of Americans continues to extend, the sheer number—although not necessarily the proportion—of persons experiencing mental disorders of late life will expand, confronting our society with unprecedented challenges in organizing, financing, and delivering effective mental health services for this population. An essential part of the needed societal response will include recognizing and devising innovative ways of supporting the increasingly more prominent role that families are assuming in caring for older, mentally impaired and mentally ill family members.

Chapter 3: Children and Mental Health

- Childhood is characterized by periods of transition and reorganization, making it critical to assess the mental health of children and adolescents in the context of familial, social, and cultural expectations about age-appropriate thoughts, emotions, and behavior.

- The range of what is considered "normal" is wide; still, children and adolescents can and do develop mental disorders that are more severe than the "ups and downs" in the usual course of development.
- Approximately one in five children and adolescents experiences the signs and symptoms of a DSM-IV disorder during the course of a year, but only about 5 percent of all children experience what professionals term "extreme functional impairment."
- Mental disorders and mental health problems appear in families of all social classes and of all backgrounds. No one is immune. Yet there are children who are at greatest risk by virtue of a broad array of factors. These include physical problems; intellectual disabilities (retardation); low birth weight; family history of mental and addictive disorders; multigenerational poverty; and caregiver separation or abuse and neglect.
- Preventive interventions have been shown to be effective in reducing the impact of risk factors for mental disorders and improving social and emotional development by providing, for example, educational programs for young children, parent-education programs, and nurse home visits.
- A range of efficacious psychosocial and pharmacologic treatments exists for many mental disorders in children, including attention-deficit/hyperactivity disorder, depression, and the disruptive disorders.
- Research is under way to demonstrate the effectiveness of most treatments for children in actual practice settings (as opposed to evidence of "efficacy" in controlled research settings), and significant barriers exist to receipt of treatment.
- Primary care and the schools are major settings for the potential recognition of mental disorders in children and adolescents, yet trained staff are limited, as are options for referral to specialty care.
- The multiple problems associated with "serious emotional disturbance" in children and adolescents are best addressed with a "systems" approach in which multiple service sectors work in an organized, collaborative way. Research on the effectiveness of systems of care shows positive results for system outcomes and functional outcomes for children; however, the relationship between changes at the system level and clinical outcomes is still unclear.
- Families have become essential partners in the delivery of mental health services for children and adolescents.
- Cultural differences exacerbate the general problems of access to appropriate mental health services. Culturally appropriate services have been designed but are not widely available.

Chapter 4: Adults and Mental Health

- As individuals move into adulthood, developmental goals focus on productivity and intimacy including pursuit of education, work, leisure, creativity, and personal relationships. Good mental health enables individuals to cope with adversity while pursuing these goals.
- Untreated, mental disorders can lead to lost productivity, unsuccessful relationships, and significant distress and dysfunction. Mental illness in adults can have a significant and continuing effect on children in their care.
- Stressful life events or the manifestation of mental illness can disrupt the balance adults seek in life and result in distress and dysfunction. Severe or life-threatening trauma experienced either in childhood or adulthood can further provoke emotional and behavioral reactions that jeopardize mental health.
- Research has improved our understanding of mental disorders in the adult stage of the life cycle. Anxiety, depression, and schizophrenia, particularly, present special problems in this age group. Anxiety and depression contribute to the high rates of suicide in this population. Schizophrenia is the most persistently disabling condition, especially for young adults, in spite of recovery of function by some individuals in mid to late life.
- Research has contributed to our ability to recognize, diagnose, and treat each of these conditions effectively in terms of symptom control and behavior management. Medication and other ther-

apies can be independent, combined, or sequenced depending on the individual's diagnosis and per- sonal preference.

- A new recovery perspective is supported by evidence on rehabilitation and treatment as well as by the personal experiences of consumers.
- Certain common events of midlife (e.g., divorce or other stressful life events) create mental health problems (not necessarily disorders) that may be addressed through a range of interventions.
- Care and treatment in the real world of practice do not conform to what research determines is best. For many reasons, at times care is inadequate, but there are models for improving treatment.
- Substance abuse is a major co-occurring problem for adults with mental disorders. Evidence supports combined treatment, although there are substantial gaps between what research recommends and what typically is available in communities.
- Sensitivity to culture, race, gender, disability, poverty, and the need for consumer involvement are important considerations for care and treatment.
- Barriers of access exist in the organization and financing of services for adults. There are specific problems with Medicare, Medicaid, income supports, housing, and managed care.

Chapter 5: Older Adults and Mental Health

- Important life tasks remain for individuals as they age. Older individuals continue to learn and contribute to the society, in spite of physiologic changes due to aging and increasing health problems.
- Continued intellectual, social, and physical activity throughout the life cycle are important for the maintenance of mental health in late life.
- Stressful life events, such as declining health and/or the loss of mates, family members, or friends often increase with age. However, persistent bereavement or serious depression is not "normal" and should be treated.
- Normal aging is not characterized by mental or cognitive disorders. Mental or substance use disorders that present alone or co-occur should be recognized and treated as illnesses.
- Disability due to mental illness in individuals over 65 years old will become a major public health problem in the near future because of demographic changes. In particular, dementia, depression, and schizophrenia, among other conditions, will all present special problems in this age group:
  - — Dementia produces significant dependency and is a leading contributor to the need for costly long-term care in the last years of life;
  - — Depression contributes to the high rates of suicide among males in this population; and
  - — Schizophrenia continues to be disabling in spite of recovery of function by some individuals in mid to late life.
- There are effective interventions for most mental disorders experienced by older persons (for example, depression and anxiety), and many mental health problems, such as bereavement.
- Older individuals can benefit from the advances in psychotherapy, medication, and other treatment interventions for mental disorders enjoyed by younger adults, when these interventions are modified for age and health status.
- Treating older adults with mental disorders accrues other benefits to overall health by improving the interest and ability of individuals to care for themselves and follow their primary care provider's directions and advice, particularly about taking medications.
- Primary care practitioners are a critical link in identifying and addressing mental disorders in older adults. Opportunities are missed to improve mental health and general medical outcomes when mental illness is underrecognized and undertreated in primary care settings.
- Barriers to access exist in the organization and financing of services for aging citizens. There are specific problems with Medicare, Medicaid, nursing homes, and managed care.

Chapter 6: Organization and Financing of Mental Health Services

In the United States in the late 20th century, research-based capabilities to identify, treat, and, in some instances, prevent mental disorders are outpacing the capacities of the existing service system to deliver mental health care to all who would benefit from it. Approximately 10 percent of children and adults receive mental health services from mental health specialists or general medical providers in a given year. Approximately one in six adults, and one in five children, obtain mental health services either from health care providers, the clergy, social service agencies, or schools in a given year.

Chapter 6 discusses the organization and financing of mental health services. The chapter provides an overview of the current system of mental health services, describing where people get care and how they use services. The chapter then presents information on the costs of care and trends in spending. Only within recent decades, in the face of concerns about discriminatory policies in mental health financing, have the dynamics of insurance financing become a significant issue in the mental health field. In particular, policies that have emphasized cost containment have ushered in managed care. Intensive research currently is addressing both positive and adverse effects of managed care on access and quality, generating information that will guard against untoward consequences of aggressive cost-containment policies. Inequities in insurance coverage for mental health and general medical care—the product of decades of stigma and discrimination—have prompted efforts to correct them through legislation designed to produce financing changes and create parity. Parity calls for equality between mental health and other health coverage.

- Epidemiologic surveys indicate that one in five Americans has a mental disorder in any one year.
- Fifteen percent of the adult population use some form of mental health service during the year. Eight percent have a mental disorder; 7 percent have a mental health problem.
- Twenty-one percent of children ages 9 to 17 receive mental health services in a year.
- The U.S. mental health service system is complex and connects many sectors (public–private, specialty–general health, health–social welfare, housing, criminal justice, and education). As a result, care may become organizationally fragmented, creating barriers to access. The system is also financed from many funding streams, adding to the complexity, given sometimes competing incentives between funding sources.
- In 1996, the direct treatment of mental disorders, substance abuse, and Alzheimer's disease cost the Nation $99 billion; direct costs for mental disorders alone totaled $69 billion. In 1990, indirect costs for mental disorders alone totaled $79 billion.
- Historically, financial barriers to mental health services have been attributable to a variety of economic forces and concerns (e.g., market failure, adverse selection, moral hazard, and public provision). This has accounted for differential resource allocation rules for financing mental health services.
  - — "Parity" legislation has been a partial solution to this set of problems.
  - — Implementing parity has resulted in negligible cost increases where the care has been managed.
- In recent years, managed care has begun to introduce dramatic changes into the organization and financing of health and mental health services.
- Trends indicate that in some segments of the private sector per capita mental health expenditures have declined much faster than they have for other conditions.
- There is little direct evidence of problems with quality in well-implemented managed care programs. The risk for more impaired populations and children remains a serious concern.
- An array of quality monitoring and quality improvement mechanisms has been developed, although incentives for their full implementation have yet to emerge. In addition, competition on the basis of quality is only beginning in the managed care industry.
- There is increasing concern about consumer satisfaction and consumers' rights. A Consumers Bill of Rights has been developed and implemented in Federal Employee Health Benefit Plans, with

broader legislation currently pending in the Congress.

Chapter 7: Confidentiality of Mental Health Information: Ethical, Legal, and Policy Issues

In an era in which the confidentiality of all health care information, its accessibility, and its uses are of concern to all Americans, privacy issues are keenly felt in the mental health field. An assurance of confidentiality is understandably critical in individual decisions to seek mental health treatment. Although an extensive legal framework governs confidentiality of consumer-provider interactions, potential problems exist and loom ever larger.

- People's willingness to seek help is contingent on their confidence that personal revelations of mental distress will not be disclosed without their consent.
- The U.S. Supreme Court recently has upheld the right to the privacy of these records and the therapist-client relationship.
- Although confidentiality issues are common to health care in general, there are special concerns for mental health care and mental health care records because of the extremely personal nature of the material shared in treatment.
- State and Federal laws protect the confidentiality of health care information but are often incomplete because of numerous exceptions which often vary from state to state. Several states have implemented or proposed models for protecting privacy that may serve as a guide to others.
- States, consumers, and family advocates take differing positions on disclosure of mental health information without consent to family caregivers. In states that allow such disclosure, information provided is usually limited to diagnosis, prognosis, and information regarding treatment, specifically medication.
- When conducting mental health research, it is in the interest of both the researcher and the individual participant to address informed consent and to obtain certificates of confidentiality before proceeding. Federal regulations require informed consent for research being conducted with Federal funds.
- New approaches to managing care and information technology threaten to further erode the confidentiality and trust deemed so essential between the direct provider of mental health services and the individual receiving those services. It is important to monitor advances so that confidentiality of records is enhanced, instead of impinged upon, by technology.
- Until the stigma associated with mental illnesses is addressed, confidentiality of mental health information will continue to be a critical point of concern for payers, providers, and consumers.

Chapter 8: A Vision for the Future—Actions for Mental Health in the New Millennium

The extensive literature that the Surgeon General's report reviews and summarizes leads to the conclusion that ***a range of treatments of documented efficacy exists for most mental disorders***. Moreover, a person may choose a particular approach to suit his or her needs and preferences. Based on this finding, the report's principal recommendation to the American people is to ***seek help if you have a mental health problem or think you have symptoms of a mental disorder***. As noted earlier, stigma interferes with the willingness of many people—even those who have a serious mental illness—to seek help. And, as documented in this report, those who do seek help will all too frequently learn that there are substantial gaps in the availability of state-of-the-art mental health services and barriers to their accessibility. Accordingly, the final chapter of the report goes on to explore opportunities to overcome barriers to implementing the recommendation and to have seeking help lead to effective treatment.

The final chapter identifies the following courses of action.

- ***Continue to Build the Science Base***: Today, integrative neuroscience and molecular genetics present some of the most exciting basic research opportunities in medical science. A plethora of new pharmacologic agents and psychotherapies for mental disorders afford new treatment opportunities but also challenge the scientific community to develop new approaches to clinical and health services interventions research. Because the vitality and feasibility of clinical research hinges on the willing participation of clinical research volunteers, it is important for society to ensure that concerns about protections for vulnerable research subjects are addressed. Responding to the calls of managed mental and behavioral health care systems for evidence-based interventions will have a much needed and discernible impact on practice. Special effort is required to address pronounced gaps in the mental health knowledge base. Key among these are the urgent need for evidence which supports strategies for mental health promotion and illness prevention. Additionally, research that explores approaches for reducing risk factors and strength- ening protective factors for the prevention of men- tal illness should be encouraged. As noted through- out the report, high-quality research and the ef- fective services it promotes are a potent weapon against stigma.

- ***Overcome Stigma***: Powerful and pervasive, stigma prevents people from acknowledging their own mental health problems, much less disclosing them to others. For our Nation to reduce the burden of mental illness, to improve access to care, and to achieve urgently needed knowledge about the brain, mind, and behavior, stigma must no longer be tolerated. Research on brain and behavior that continues to generate ever more effective treatments for mental illnesses is a potent antidote to stigma. The issuance of this Surgeon General's Report on Mental Health seeks to help reduce stigma by dispelling myths about mental illness, by providing accurate knowledge to ensure more informed consumers, and by encouraging help seeking by individuals experiencing mental health problems.
- ***Improve Public Awareness of Effective Treatment***: Americans are often unaware of the choices they have for effective mental health treatments. In fact, there exists a constellation of several treatments of documented efficacy for most mental disorders. Treatments fall mainly under several broad categories—counseling, psychotherapy, medication therapy, rehabilitation—yet within each category are many more choices. All human services professionals, not just health professionals, have an obligation to be better informed about mental health treatment resources in their communities and should encourage individuals to seek help from any source in which they have confidence.
- ***Ensure the Supply of Mental Health Services and Providers***: The fundamental components of effective service delivery, which include integrated community-based services, continuity of providers and treatments, family support services (including psychoeducation), and culturally sensitive services, are broadly agreed upon, yet certain of these and other mental health services are in consistently short supply, both regionally and, in some instances, nationally. Because the service system as a whole, as opposed to treatment services considered in isolation, dictates the outcome of recovery-oriented mental health care, it is imperative to expand the supply of effective, evidence-based services throughout the Nation. Key personnel shortages include mental health professionals serving children/adolescents and older people with serious mental disorders and specialists with expertise in cognitive-behavioral therapy and interpersonal therapy, two forms of psychotherapy that research has shown to be effective for several severe mental disorders. For adults and children with less severe conditions, primary health care, the schools, and other human services must be prepared to assess and, at times, to treat individuals who come seeking help.
- ***Ensure Delivery of State-of-the-Art Treatments***: A wide variety of effective, community-based services, carefully refined through years of research, exist for even the most severe mental illnesses yet are not being translated into community settings. Numerous explanations for the gap between what is known from research and what is

practiced beg for innovative strategies to bridge it.

- ***Tailor Treatment to Age, Gender, Race, and Culture***: Mental illness, no less than mental health, is influenced by age, gender, race, and culture as well as additional facets of diversity that can be found within all of these population groups—for example, physical disability or a person's sexual orientation. To be effective, the diagnosis and treatment of mental illness must be tailored to all characteristics that shape a person's image and identity. The consequences of not understanding these influences can be profoundly deleterious. "Culturally competent" services incorporate understanding of racial and ethnic groups, their histories, traditions, beliefs, and value systems. With appropriate training and a fundamental respect for clients, any mental health professional can provide culturally competent services that reflect sensitivity to individual differences and, at the same time, assign validity to an individual's group identity. Nonetheless, the preference of many members of ethnic and racial minority groups to be treated by mental health professionals of similar background underscores the need to redress the current insufficient supply of mental health professionals who are members of racial and ethnic minority groups.
- ***Facilitate Entry Into Treatment***: Public and private agencies have an obligation to facilitate entry into mental health care and treatment through the multiple "portals of entry" that exist: primary health care, schools, and the child welfare system. To enhance adherence to treatment, agencies should offer services that are responsive to the needs and preferences of service users and their families. At the same time, some agencies receive inappropriate referrals. For example, an alarming number of children and adults with mental illness are in the criminal justice system inappropriately. Importantly, assuring the small number of individuals with severe mental disorders who pose a threat of danger to themselves or others ready access to adequate and appropriate services promises to reduce significantly the *need* for coercion in the form of involuntary commitment to a hospital and/or certain outpatient treatment requirements that have been legislated in most states and territories. Coercion should not be a substitute for effective care that is sought voluntarily; consensus on this point testifies to the need for research designed to enhance adherence to treatment.
- ***Reduce Financial Barriers to Treatment***: Concerns about the cost of care—concerns made worse by the disparity in insurance coverage for mental disorders in contrast to other illnesses—are among the foremost reasons why people do not seek needed mental health care. While both access to and use of mental health services increase when benefits for those services are enhanced, preliminary data show that the effectiveness—and, thus, the value—of mental health care also has increased in recent years, while expenditures for services, under managed care, have fallen. Equality between mental health coverage and other health coverage—a concept known as parity—is an affordable and effective objective.

Scope of Coverage of the Report

This report is comprehensive but not exhaustive in its coverage of mental health and mental illness. It considers mental health facets of some conditions which are not always associated with the mental disorders and does not consider all conditions which can be found in classifications of mental disorders such as DSM-IV. The report includes, for example, a discussion of autism in Chapter 3 and provides an extensive section on Alzheimer's disease in Chapter 5. Although DSM-IV lists specific mental disorder criteria for both of these conditions, they often are viewed as being outside the scope of the mental health field. In both cases, mental health professionals are involved in the diagnosis and treatment of these conditions, often characterized by cognitive and behavioral impairments. Developmental disabilities and mental retardation are not discussed except in passing in this report. These conditions were considered to be beyond its scope with a care system all their own and very special needs. The same is generally true for the addictive disorders, such as alcohol and other drug use disorders. The latter, however, co-occur with such frequency with the other mental disorders, which are the focus of this report, that the co-occurrence is discussed throughout. The report addresses the epidemiology of addictive disorders and their co-occurrence with other mental disorders as well as the treatment of co-occurring conditions. Brief sections on substance abuse in adolescence and late life also are included in the report.

Preparation of the Report

In September 1997, the Office of the Surgeon General, with the approval of the Secretary of the Department of Health and Human Services, authorized the Substance Abuse and Mental Health Services Administration (SAMHSA) to serve as lead operating division for preparing the Surgeon General's Report on Mental Health. SAMHSA's Center for Mental Health Services worked in partnership with the National Institute of Mental Health, National Institutes of Health, to develop this report under the guidance of Surgeon General David Satcher, M.D., Ph.D. The Federal partners established a Planning Board comprising individuals who represent a broad range of expertise in mental health: university-based researchers and educators, practicing mental health professionals, self-identified consumers of mental health services, and many knowledgeable advocates in diverse areas of the mental health field. Also included on the Planning Board were individuals representing Federal Operating Divisions, Offices, Centers, and Institutes and private nonprofit foundations with interests in the area of mental health.

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CHAPTER 1

INTRODUCTION AND THEMES

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CHAPTER 1

INTRODUCTION AND THEMES

This first Surgeon General's Report on Mental Health is issued at the culmination of a half-century that has witnessed remarkable advances in the understanding of mental disorders and the brain and in our appreciation of the centrality of mental health to overall health and well-being. The report was prepared against a backdrop of growing awareness in the United States and throughout the world of the immense burden of disability associated with mental illnesses. In the United States, mental disorders collectively account for more than 15 percent of the overall burden of disease from *all* causes and slightly more than the burden associated with all forms of cancer (Murray & Lopez, 1996). These data underscore the importance and urgency of treating and preventing mental disorders and of promoting mental health in our society.

The report in its entirety provides an up-to-date review of scientific advances in the study of mental health and of mental illnesses that affect at least one in five Americans. Several important conclusions may be drawn from the extensive scientific literature summarized in the report. One is that a variety of treatments of well-documented efficacy exist for the array of clearly defined mental and behavioral disorders that occur across the life span. Every person should be encouraged to seek help when questions arise about mental health, just as each person is encouraged to seek help when questions arise about health. Research highlighted in the report demonstrates that mental health is a facet of health that evolves throughout the lifetime. Just as each person can do much to promote and maintain overall health regardless of age, each also can do much to promote and strengthen mental health at every stage of life.

Much remains to be learned about the causes, treatment, and prevention of mental and behavioral disorders. Obstacles that may limit the availability or accessibility of mental health services for some Americans are being dismantled, but disparities persist. Still, thanks to research and the experiences of millions of individuals who have a mental disorder, their family members, and other advocates, the Nation has the power today to tear down the most formidable obstacle to future progress in the arena of mental illness and health. That obstacle is stigma. Stigmatization of mental illness is an excuse for inaction and discrimination that is inexcusably outmoded in 1999. As evident in the chapters that follow, we have acquired an immense amount of knowledge that permits us, as a Nation, to respond to the needs of persons with mental illness in a manner that is both effective and respectful.

Overarching Themes

Mental Health and Mental Illness: A Public Health Approach

The Nation's contemporary mental health enterprise, like the broader field of health, is rooted in a population-based public health model. The public health model is characterized by concern for the health of a population in its entirety and by awareness of the linkage between health and the physical and psychosocial environment. Public health focuses not only on traditional areas of diagnosis, treatment, and etiology, but also on epidemiologic surveillance of the health of the population at large, health promotion, disease prevention, and access to and evaluation of services (Last & Wallace, 1992).

Just as the mainstream of public health takes a broad view of health and illness, this Surgeon General's Report on Mental Health takes a wide-angle lens to *both* mental health and mental illness. In years past, the mental health field often focused principally on mental illness in order to serve individuals who were most severely affected. Only as the field has matured has it begun to respond to intensifying interest and concerns about disease prevention and health promotion. Because of the more recent consideration of these topic areas, the body of accumulated knowledge regarding them is not as expansive as that for mental illness.

Mental Disorders are Disabling

The burden of mental illness on health and productivity in the United States and throughout the world has long been profoundly underestimated. Data developed by the massive Global Burden of Disease study,[1] conducted by the World Health Organization, the World Bank, and Harvard University, reveal that mental illness, including suicide,[2] ranks second in the burden of disease in established market economies, such as the United States (Table 1-1).

Mental illness emerged from the Global Burden of Disease study as a surprisingly significant contributor to the burden of disease. The measure of calculating disease burden in this study, called Disability Adjusted Life Years (DALYs), allows comparison of the burden of disease across many different disease conditions. DALYs account for lost years of healthy life regardless of whether the years were lost to premature death or disability. The disability component of this measure is weighted for severity of the disability. For example, major depression is equivalent in burden to blindness or paraplegia, whereas active psychosis seen in schizophrenia is equal in disability burden to quadriplegia.

Table 1-1. Disease burden by selected illness categories in established market economies, 1990

	Percent of Total DALYs*
All cardiovascular conditions	18.6
All mental illness**	15.4
All malignant diseases (cancer)	15.0
All respiratory conditions	4.8
All alcohol use	4.7
All infectious and parasitic diseases	2.8
All drug use	1.5

*Disability-adjusted life year (DALY) is a measure that expresses years of life lost to premature death and years lived with a disability of specified severity and duration (Murray & Lopez, 1996).

**Disease burden associated with "mental illness" includes suicide.

By this measure, major depression alone ranked second only to ischemic heart disease in magnitude of disease burden (see Table 1-2). Schizophrenia, bipolar disorder, obsessive-compulsive disorder, panic disorder, and post-traumatic stress disorder also contributed significantly to the burden represented by mental illness.

Table 1-2. Leading sources of disease burden in established market economies, 1990

		Total DALYs (millions)	Percent of Total
	All causes	98.7	
1	Ischemic heart disease	8.9	9.0
2	**Unipolar major depression**	**6.7**	**6.8**
3	Cardiovascular disease	5.0	5.0
4	Alcohol use	4.7	4.7
5	Road traffic accidents	4.3	4.4

Source: Murray & Lopez, 1996.

Mental Health and Mental Illness: Points on a Continuum

As will be evident in the pages that follow, "mental health" and "mental illness" are not polar opposites but may be thought of as points on a continuum. *Mental health* is a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity. Mental health is indispensable to personal well-being, family and interpersonal relationships, and contribution to community or society. It is easy to overlook the value of mental health until problems surface. Yet from early childhood until death, mental health is the springboard of thinking and communication skills, learning, emotional growth, resilience, and self-esteem. These

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[1] Murray & Lopez, 1996.

[2] The Surgeon General issued a Call to Action on Suicide in 1999, reflecting the public health magnitude of this consequence of mental illness. The Call to Action is summarized in Figure 4-1.

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are the ingredients of each individual's successful contribution to community and society. Americans are inundated with messages about *success*—in school, in a profession, in parenting, in relationships—without appreciating that successful performance rests on a foundation of mental health.

Many ingredients of mental health may be identifiable, but mental health is not easy to define. In the words of a distinguished leader in the field of mental health prevention, "... built into any definition of wellness . . . are overt and covert expressions of values. Because values differ across cultures as well as among subgroups (and indeed individuals) within a culture, the ideal of a uniformly acceptable definition of the constructs is illusory" (Cowen, 1994). In other words, what it means to be mentally healthy is subject to many different interpretations that are rooted in value judgments that may vary across cultures. The challenge of defining mental health has stalled the development of programs to foster mental health (Secker, 1998), although strides have been made with wellness programs for older people (Chapter 5).

Mental illness is the term that refers collectively to all diagnosable mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning. Alzheimer's disease exemplifies a mental disorder largely marked by alterations in thinking (especially forgetting). Depression exemplifies a mental disorder largely marked by alterations in mood. Attention-deficit/hyperactivity disorder exemplifies a mental disorder largely marked by alterations in behavior (overactivity) and/or thinking (inability to concentrate). Alterations in thinking, mood, or behavior contribute to a host of problems—patient distress, impaired functioning, or heightened risk of death, pain, disability, or loss of freedom (American Psychiatric Association, 1994).

This report uses the term "mental health problems" for signs and symptoms of insufficient intensity or duration to meet the criteria for any mental disorder. Almost everyone has experienced mental health problems in which the distress one feels matches some of the signs and symptoms of mental disorders. Mental health problems may warrant active efforts in health promotion, prevention, and treatment. Bereavement symptoms in older adults offer a case in point. Bereavement symptoms of less than 2 months' duration do not qualify as a mental disorder, according to professional manuals for diagnosis (American Psychiatric Association, 1994). Nevertheless, bereavement symptoms can be debilitating if they are left unattended. They place older people at risk for depression, which, in turn, is linked to death from suicide, heart attack, or other causes (Zisook & Shuchter, 1991, 1993; Frasure-Smith et al., 1993, 1995; Conwell, 1996). Much can be done—through formal treatment or through support group participation—to ameliorate the symptoms and to avert the consequences of bereavement. In this case, early intervention is needed to address a mental health problem before it becomes a potentially life-threatening disorder.

Mind and Body are Inseparable

Considering health and illness as points along a continuum helps one appreciate that neither state exists in pure isolation from the other. In another but related context, everyday language tends to encourage a misperception that "mental health" or "mental illness" is unrelated to "physical health" or "physical illness." In fact, the two are inseparable.

Seventeenth-century philosopher Rene Descartes conceptualized the distinction between the mind and the body. He viewed the "mind" as completely separable from the "body" (or "matter" in general). The mind (and spirit) was seen as the concern of organized religion, whereas the body was seen as the concern of physicians (Eisendrath & Feder, in press). This partitioning ushered in a separation between so-called "mental" and "physical" health, despite advances in the 20th century that proved the interrelationships between mental and physical health (Cohen & Herbert, 1996; Baum & Posluszny, 1999).

Although "mind" is a broad term that has had many different meanings over the centuries, today it refers to the totality of mental functions related to thinking, mood, and purposive behavior. The mind is generally seen as deriving from activities within the brain but displaying emergent properties, such as consciousness (Fischbach, 1992; Gazzaniga et al., 1998).

One reason the public continues to this day to emphasize the difference between mental and physical health is embedded in language. Common parlance continues to use the term "physical" to distinguish some forms of health and illness from "mental" health and illness. People continue to see mental and physical as separate functions when, in fact, mental functions (e.g., memory) are physical as well (American Psychiatric Association, 1994). Mental functions are carried out by the brain. Likewise, mental disorders are reflected in physical changes in the brain (Kandel, 1998). Physical changes in the brain often trigger physical changes in other parts of the body too. The racing heart, dry mouth, and sweaty palms that accompany a terrifying nightmare are orchestrated by the brain. A nightmare is a mental state associated with alterations of brain chemistry that, in turn, provoke unmistakable changes elsewhere in the body.

Instead of dividing physical from mental health, the more appropriate and neutral distinction is between "mental" and "somatic" health. Somatic is a medical term that derives from the Greek word *soma* for the body. Mental health refers to the successful performance of mental functions in terms of thought, mood, and behavior. Mental disorders are those health conditions in which alterations in mental functions are paramount. Somatic conditions are those in which alterations in nonmental functions predominate. While the brain carries out all mental functions, it also carries out some somatic functions, such as movement, touch, and balance. That is why not all brain diseases are mental disorders. For example, a stroke causes a lesion in the brain that may produce disturbances of movement, such as paralysis of limbs. When such symptoms predominate in a patient, the stroke is considered a somatic condition. But when a stroke mainly produces alterations of thought, mood, or behavior, it is considered a mental condition (e.g., dementia). The point is that a brain disease can be seen as a mental disorder or a somatic disorder depending on the functions it perturbs.

The Roots of Stigma

Stigmatization of people with mental disorders has persisted throughout history. It is manifested by bias, distrust, stereotyping, fear, embarrassment, anger, and/or avoidance. Stigma leads others to avoid living, socializing or working with, renting to, or employing people with mental disorders, especially severe disorders such as schizophrenia (Penn & Martin, 1998; Corrigan & Penn, 1999). It reduces patients' access to resources and opportunities (e.g., housing, jobs) and leads to low self-esteem, isolation, and hopelessness. It deters the public from seeking, and wanting to pay for, care. In its most overt and egregious form, stigma results in outright discrimination and abuse. More tragically, it deprives people of their dignity and interferes with their full participation in society.

Explanations for stigma stem, in part, from the misguided split between mind and body first proposed by Descartes. Another source of stigma lies in the 19th-century separation of the mental health treatment system in the United States from the mainstream of health. These historical influences exert an often immediate influence on perceptions and behaviors in the modern world.

Separation of Treatment Systems

In colonial times in the United States, people with mental illness were described as "lunaticks" and were largely cared for by families. There was no concerted effort to treat mental illness until urbanization in the early 19th century created a societal problem that previously had been relegated to families scattered among small rural communities. Social policy assumed the form of isolated asylums where persons with mental illness were administered the reigning treatments of the era. By the late 19th century, mental illness was thought to grow "out of a violation of those physical, mental and moral laws which, properly understood and obeyed, result not only in the highest development of the race, but the highest type of civilization" (cited in Grob, 1983). Throughout the history of institutionalization in asylums (later renamed mental hospitals), reformers strove to improve treatment and curtail abuse. Several waves of reform culminated in the deinstitutionalization movement that began in the 1950s with the goal of shifting patients and care to the community.

Public Attitudes About Mental Illness: 1950s to 1990s

Nationally representative surveys have tracked public attitudes about mental illness since the 1950s (Star, 1952, 1955; Gurin et al., 1960; Veroff et al., 1981). To permit comparisons over time, several surveys of the 1970s and the 1990s phrased questions exactly as they had been asked in the 1950s (Swindle et al., 1997).

In the 1950s, the public viewed mental illness as a stigmatized condition and displayed an unscientific understanding of mental illness. Survey respondents typically were not able to identify individuals as "mentally ill" when presented with vignettes of individuals who would have been said to be mentally ill according to the professional standards of the day. The public was not particularly skilled at distinguishing mental illness from ordinary unhappiness and worry and tended to see only extreme forms of behavior—namely psychosis—as mental illness. Mental illness carried great social stigma, especially linked with fear of unpredictable and violent behavior (Star, 1952, 1955; Gurin et al., 1960; Veroff et al., 1981).

By 1996, a modern survey revealed that Americans had achieved greater scientific understanding of mental illness. But the increases in knowledge did not defuse social stigma (Phelan et al., 1997). The public learned to define mental illness and to distinguish it from ordinary worry and unhappiness. It expanded its definition of mental illness to encompass anxiety, depression, and other mental disorders. The public attributed mental illness to a mix of biological abnormalities and vulnerabilities to social and psychological stress (Link et al., in press). Yet, in comparison with the 1950s, the public's perception of mental illness more frequently incorporated violent behavior (Phelan et al., 1997). This was primarily true among those who defined mental illness to include psychosis (a view held by about one-third of the entire sample). Thirty-one percent of this group mentioned violence in its descriptions of mental illness, in comparison with 13 percent in the 1950s. In other words, the perception of people with psychosis as being dangerous is stronger today than in the past (Phelan et al., 1997).

The 1996 survey also probed how perceptions of those with mental illness varied by diagnosis. The public was more likely to consider an individual with schizophrenia as having mental illness than an individual with depression. All of them were distinguished reasonably well from a worried and unhappy individual who did not meet professional criteria for a mental disorder. The desire for social distance was consistent with this hierarchy (Link et al., in press).

Why is stigma so strong despite better public understanding of mental illness? The answer appears to be fear of violence: people with mental illness, especially those with psychosis, are perceived to be more violent than in the past (Phelan et al., 1997).

This finding begs yet another question: Are people with mental disorders truly more violent? Research supports some public concerns, but the overall likelihood of violence is low. The greatest risk of violence is from those who have dual diagnoses, i.e., individuals who have a mental disorder as well as a substance abuse disorder (Swanson, 1994; Eronen et al., 1998; Steadman et al., 1998). There is a small elevation in risk of violence from individuals with severe mental disorders (e.g., psychosis), especially if they are noncompliant with their medication (Eronen et al., 1998; Swartz et al., 1998). Yet the risk of violence is much less for a stranger than for a family member or person who is known to the person with mental illness (Eronen et al., 1998). *In fact, there is very little risk of violence or harm to a stranger from casual contact with an individual who has a mental disorder.* Because the average person is ill-equipped to judge whether someone who is behaving erratically has any of these disorders, alone or in combination, the natural tendency is to be wary. Yet, to put this all in perspective, the overall contribution of mental disorders to the total level of violence in society is exceptionally small (Swanson, 1994).

Because most people should have little reason to fear violence from those with mental illness, even in its most severe forms, *why* is fear of violence so entrenched? Most speculations focus on media coverage and deinstitutionalization (Phelan et al., 1997; Heginbotham, 1998). One series of surveys found that selective media reporting reinforced the public's stereotypes linking violence and mental illness and encouraged people to distance themselves from those with mental disorders (Angermeyer & Matschinger, 1996). And yet, deinstitutionalization made this distancing impossible over the 40 years as the population of state and county mental hospitals was reduced from a high of about 560,000 in 1955 to well below 100,000 by the 1990s (Bachrach, 1996). Some advocates of deinstitutionalization expected stigma to be reduced with community care and commonplace exposure. Stigma might have been greater today had not public education resulted in a more scientific understanding of mental illness.

Stigma and Seeking Help for Mental Disorders

Nearly two-thirds of all people with diagnosable mental disorders do not seek treatment (Regier et al., 1993; Kessler et al., 1996). Stigma surrounding the receipt of mental health treatment is among the many barriers that discourage people from seeking treatment (Sussman et al., 1987; Cooper-Patrick et al., 1997). Concern about stigma appears to be heightened in rural areas in relation to larger towns or cities (Hoyt et al., 1997). Stigma also disproportionately affects certain age groups, as explained in the chapters on children and older people.

The surveys cited above concerning evolving public attitudes about mental illness also monitored how people would cope with, and seek treatment for, mental illness if they became symptomatic. (The term "nervous breakdown" was used in lieu of the term "mental illness" in the 1996 survey to allow for comparisons with the surveys in the 1950s and 1970s.) The 1996 survey found that people were likelier than in the past to approach mental illness by coping with, rather than by avoiding, the problem. They also were more likely now to want *informal* social supports (e.g., self-help groups). Those who now sought *formal* support increasingly preferred counselors, psychologists, and social workers (Swindle et al., 1997).

Stigma and Paying for Mental Disorder Treatment

Another manifestation of stigma is reflected in the public's reluctance to pay for mental health services. Public willingness to pay for mental health treatment, particularly through insurance premiums or taxes, has been assessed largely through public opinion polls. Members of the public report a greater willingness to pay for insurance coverage for individuals with severe mental disorders, such as schizophrenia and depression, rather than for less severe conditions such as worry and unhappiness (Hanson, 1998). While the public generally appears to support paying for treatment, its support diminishes upon the realization that higher taxes or premiums would be necessary (Hanson, 1998). In the lexicon of survey research, the willingness to pay for mental illness treatment services is considered to be "soft." The public generally ranks insurance coverage for mental disorders below that for somatic disorders (Hanson, 1998).

Reducing Stigma

There is likely no simple or single panacea to eliminate the stigma associated with mental illness. Stigma was expected to abate with increased knowledge of mental illness, but just the opposite occurred: stigma in some ways intensified over the past 40 years even though understanding improved. Knowledge of mental illness appears by itself insufficient to dispel stigma (Phelan et al., 1997). Broader knowledge may be warranted, especially to redress public fears (Penn & Martin, 1998). Research is beginning to demonstrate that negative perceptions about severe mental illness can be lowered by furnishing empirically based information on the association between violence and severe mental illness (Penn & Martin, 1998). Overall approaches to stigma reduction involve programs of advocacy, public education, and contact with persons with mental illness through schools and other societal institutions (Corrigan & Penn, 1999).

Another way to eliminate stigma is to find causes and effective treatments for mental disorders (Jones, 1998). History suggests this to be true. Neurosyphilis and pellagra are illustrative of mental disorders for which stigma has receded. In the early part of this century, about 20 percent of those admitted to mental hospitals had "general paresis,"- later identified as tertiary syphilis (Grob, 1994). This advanced stage of syphilis occurs when the bacterium invades the brain and causes neurological deterioration (including psychosis), paralysis, and death. The discoveries of an infectious etiology and of penicillin led to the virtual elimination of neurosyphilis. Similarly, when pellagra was traced to a nutrient deficiency, and nutritional supplementation with niacin was introduced, the condition was eventually eradicated in the developed world. Pellagra's victims with delirium had been placed in mental hospitals early in the 20th century before its etiology was clarified. Although no one has documented directly the reduction of public stigma toward these conditions over the early and later parts of this century, disease eradication through widespread acceptance of treatment (and its cost) offers indirect proof.

Ironically, these examples also illustrate a more unsettling consequence: that the mental health field was adversely affected when causes and treatments were identified. As advances were achieved, each condition was transferred from the mental health field to another medical specialty (Grob, 1991). For instance, dominion over syphilis was moved to dermatology, internal medicine, and neurology upon advances in etiology and treatment. Dominion over hormone-related mental disorders was moved to endocrinology under similar circumstances. The consequence of this transformation, according to historian Gerald Grob, is that the mental health field became over the years the repository for mental disorders whose etiology was unknown. This left the mental health field "vulnerable to accusations by their medical brethren that psychiatry was not part of medicine, and that psychiatric practice rested on superstition and myth" (Grob, 1991).

These historical examples signify that stigma dissipates for individual disorders once advances render them less disabling, infectious, or disfiguring. Yet the stigma surrounding *other* mental disorders not only persists but may be inadvertently reinforced by leaving to mental health care only those behavioral conditions without known causes or cures. To point this out is not intended to imply that advances in mental health should be halted; rather, advances should be nurtured and heralded. The purpose here is to explain some of the historical origins of the chasm between the health and mental health fields.

Stigma must be overcome. Research that will continue to yield increasingly effective treatments for mental disorders promises to be an effective antidote. When people understand that mental disorders are not the result of moral failings or limited will power, but are legitimate illnesses that are responsive to specific treatments, much of the negative stereotyping may dissipate. Still, fresh approaches to disseminate research information and, thus, to counter stigma need to be developed and evaluated. Social science research has much to contribute to the development and evaluation of anti-stigma programs (Corrigan & Penn, 1999). As stigma abates, a transformation in public attitudes should occur. People should become eager to seek care. They should become more willing to absorb its cost. And, most importantly, they should become far more receptive to the messages that are the subtext of this report: mental health and mental illness are part of the mainstream of health, and they are a concern for all people.

The Science Base of the Report

Reliance on Scientific Evidence

The statements and conclusions throughout this report are documented by reference to studies published in the scientific literature. For the most part, this report cites studies of empirical—rather than theoretical—research, peer-reviewed journal articles including reviews that integrate findings from numerous studies, and books by recognized experts. When a study has been accepted for publication but the publication has not yet appeared, owing to the delay between acceptance and final publication, the study is referred to as "in press." The report refers, on occasion, to unpublished research by means of reference to a presentation at a professional meeting or to a "personal communication" from the researcher, a practice that also is used sparingly in professional journals. These personal references are to acknowledged experts whose research is in progress.

Research Methods

Quality research rests on accepted methods of testing hypotheses. Two of the more common research methods used in the mental health field are experimental research and correlational research. Experimental research is the preferred method for assessing causation but may be too difficult or too expensive to conduct. Experimental research strives to discover cause and effect relationships, such as whether a new drug is effective for treating a mental disorder. In an experimental study, the investigator deliberately introduces an intervention to determine its consequences (i.e., the drug's efficacy). The investigator sets up an experiment comparing the effects of giving the new drug to one group of people, the experimental group, while giving a placebo (an inert pill) to another group, the so-called control group. The incorporation of a control group rules out the possibility that something other than the experimental treatment (i.e., the new drug) produces the results. The difference in outcome between the experimental and control group—which, in this case, may be the reduction or elimination of the symptoms of the disorder—then can be causally attributed to the drug. Similarly, in an experimental study of a psychological treatment, the experimental group is given a new type of psychotherapy, while the control or comparison group receives either no psychotherapy or a different form of psychotherapy. With both pharmacological and psychological studies, the best way to assign study participants, called subjects, either to the treatment or the control (or comparison) group is by assigning them randomly to different treatment groups. Randomization reduces bias in the results. An experimental study in humans with randomization is called a randomized controlled trial.

Correlational research is employed when experimental research is logistically, ethically, or financially impossible. Instead of deliberately introducing an intervention, researchers observe relationships to uncover whether two factors are associated, or correlated. Studying the relationship between stress and depression is illustrative. It would be unthinkable to introduce seriously stressful events to see if they cause depression. A correlational study in this case would compare a group of people already experiencing high levels of stress with another group experiencing low levels of stress to determine whether the high-stress group is more likely to develop depression. If this happens, then the results would indicate that high levels of stress are associated with depression. The limitation of this type of study is that it only can be used to establish associations, not cause and effect relationships. (The positive relationship between stress and depression is discussed most thoroughly in Chapter 4.)

Controlled studies—that is, studies with control or comparison groups—are considered superior to uncontrolled studies. But not every question in mental health can be studied with a control or comparison group. Findings from an uncontrolled study may be better than no information at all. An uncontrolled study also may be beneficial in generating hypotheses or in testing the feasibility of an intervention. The results presumably would lead to a controlled study. In short, uncontrolled studies offer a good starting point but are never conclusive by themselves.

Levels of Evidence

In science, no single study by itself, however well designed, is generally considered sufficient to establish causation. The findings need to be replicated by other investigators to gain widespread acceptance by the scientific community.

The strength of the evidence amassed for any scientific fact or conclusion is referred to as "the level of evidence." The level of evidence, for example, to justify the entry of a new drug into the marketplace has to be substantial enough to meet with approval by the U.S. Food and Drug Administration (FDA). According to U.S. drug law, a new drug's safety and efficacy must be established through controlled clinical trials conducted by the drug's manufacturer or sponsor (FDA, 1998). The FDA's decision to approve a drug represents the culmination of a lengthy, research-intensive process of drug development, which often consumes years of animal testing followed by human clinical trials (DiMasi & Lasagna, 1995). The FDA requires three phases of clinical trials[3] before a new drug can be approved for marketing (FDA, 1998).

With psychotherapy, the level of evidence similarly must be high. Although there are no formal Federal laws governing which psychotherapies can be introduced into practice, professional groups and experts in the field strive to assess the level of evidence in a given area through task forces, review articles, and other methods for evaluating the body of published studies on a topic. This Surgeon General's report is replete with references to such evaluations. One of the most prominent series of evaluations was set in motion by a group within the American Psychological Association (APA), one of the main professional organizations of psychologists. Beginning in the mid-1990s, the APA's Division of Clinical Psychology convened task forces with the objective of establishing which psychotherapies were of proven efficacy. To guide their evaluation, the first task force created a set of criteria that also was used or adapted by subsequent task forces. The first task force actually developed two sets of criteria: the first, and more rigorous, set of criteria was for *Well-Established Treatments*, while the other set was for *Probably Efficacious Treatments* (Chambless et al., 1996). For a psychotherapy to be well established, at least two experiments with group designs or similar types of studies must have been published to demonstrate efficacy. Chapters 3 through 5 of this report describe the findings of the task forces in relation to psychotherapies for children, adults, and older adults. Some types of psychotherapies that do not meet the criteria might be effective but may not have been studied sufficiently.

Another way of evaluating a collection of studies is through a formal statistical technique called a meta-analysis. A meta-analysis is a way of combining results from multiple studies. Its goal is to determine the size and consistency of the "effect" of a particular treatment or other intervention observed across the studies. The statistical technique makes the results of different studies comparable so that an overall "effect size" for the treatment can be identified. A meta-analysis determines if there is consistent evidence of a statistically significant effect of a specified treatment and estimates the size of the effect, according to widely accepted standards for a small, medium, or large effect.

Overview of the Report's Chapters

The preceding sections have addressed overarching themes in the body of the report. This section provides a brief overview of the entire report, including a description of its general orientation and a summary of key conclusions drawn from each chapter.

Chapter 2 begins with an overview of research under way today that is focused on the brain and behavior in mental health and mental illness. It explains how newer approaches to neuroscience are mending the mind-body split, which for so long has been a stumbling block to understanding the relationship of the brain to behavior, thought, and emotion. Modern integrative neuroscience offers a means of linking research on broad "systems-level" aspects of brain function with the remarkably detailed tools and findings of molecular genetics. There follows an overview of mental illness that highlights topics including symptoms, diagnosis, epidemiology (i.e., research having to do with the distribution and determinants of mental disorders in population groups), and cost, all of which are discussed in the context of specific disorders throughout the report. The section on etiology reviews research that is seeking to define, with ever greater precision, the causes of mental illnesses. As will be seen, etiology research must examine fundamental biological and behavioral processes, as well as a necessarily broad array of life events. No less than research on normal healthy development, etiological research underscores the inextricability of nature and nurture, or biological and psychosocial influences, in mental illness. The section on development of temperament reveals how mental health research has attempted over much of the past century to understand how biological, psychological, and sociocultural factors meld in health as well as illness. The chapter then reviews research approaches to the prevention and treatment of mental disorders and provides an overview of mental health services and their delivery. Final sections cover the growing influence on the mental health field of cultural diversity, the importance of consumerism, and new optimism about recovery from mental illness.

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[3] The first phase is to establish safety (Phase I), while the latter two phases establish efficacy through small and then large-scale randomized controlled clinical trials (Phases II and III) (FDA, 1998).

Chapters 3, 4, and 5 capture the breadth, depth, and vibrancy of the mental health field. The chapters probe mental health and mental illness in children and adolescents, in adulthood (i.e., in persons up to ages 55 to 65), and in older adults, respectively. This life span approach reflects awareness that mental health, and the brain and behavioral disorders that impinge upon it, are dynamic, ever-changing phenomena that, at any given moment, reflect the sum total of every person's genetic inheritance and life experiences. The brain is extraordinarily "plastic," or malleable. It interacts with and responds—both in its function and in its very structure—to multiple influences continuously, across every stage of life. Variability in expression of mental health and mental illness over the life span can be very subtle or very pronounced. As an example, the symptoms of separation anxiety are normal in early childhood but are signs of distress in later childhood and beyond. It is all too common for people to appreciate the impact of developmental processes in children yet not to extend that conceptual understanding to older people. In fact, older people continue to develop and change. Different stages of life are associated with distinct forms of mental and behavioral disorders and with distinctive capacities for mental health.

With rare exceptions, few persons are destined to a life marked by unremitting, acute mental illness. The most severe, persistent forms of mental illness tend to be amenable to treatment, even when recurrent and episodic. As conditions wax and wane, opportunities exist for interventions. The goal of an intervention at any given time may vary. The focus may be on recovery, prevention of recurrence, or the acquisition of knowledge or skills that permit more effective management of an illness. Chapters 3 through 5 cover a uniform list of topics most relevant to each age cluster. Topics include mental health; prevention, diagnosis, and treatment of mental illness; service delivery; and other services and supports.

It would be impractical for a report of this type to attempt to address every domain of mental health and mental illness; therefore, this report casts a spotlight on selected topics in each of Chapters 3 through 5. The various disorders featured in depth in a given chapter were selected on the basis of their prevalence and the clinical, societal, and economic burden associated with each. To the extent that data permit, the report takes note of how gender and culture, in addition to age, influence the diagnosis, course, and treatment of mental illness. The chapters also note the changing role of consumers and families, with attention to informal support services (i.e., unpaid services) with which patients are so comfortable (Phelan et al., 1997) and upon which they depend for information. Patients and families welcome a proliferating array of support services—such as self-help programs, family self-help, crisis services, and advocacy—that help them cope with the isolation, family disruption, and possible loss of employment and housing that may accompany mental disorders. Support services can help dissipate stigma and guide patients into formal care as well.

Although the chapters that address stages of development afford a sense of the breadth of issues pertinent to mental health and illness, the report is not exhaustive. The neglect of any given disorder, population, or topic should not be construed as signifying a lack of importance.

Chapter 6 discusses the organization and financing of mental health services. The first section provides an overview of the current system of mental health services, describing where people get care and how they use services. The chapter then presents information on the costs of care and trends in spending. Only within recent decades have the dynamics of insurance financing become a significant issue in the mental health field; these are discussed, as is the advent of managed care. The chapter addresses both positive and adverse effects of managed care on access and quality and describes efforts to guard against untoward consequences of aggressive cost-containment policies. The final section documents some of the inequities between general health care and mental health care and describes efforts to correct them through legislative regulation and financing changes.

The confidentiality of all health care information has emerged as a core issue in recent years, as concerns regarding the accessibility of health care information and its uses have risen. As Chapter 7 illustrates, privacy concerns are particularly keenly felt in the mental health field, beginning with the importance of an assurance of confidentiality in individual decisions to seek mental health treatment. The chapter reviews the legal framework governing confidentiality and potential problems with that framework, and policy issues that must be addressed by those concerned with the confidentiality of mental health and substance abuse information.

Chapter 8 concludes, on the basis of the extensive literature that the Surgeon General's report reviews and summarizes, that ***the efficacy of mental health treatment is well-documented***. Moreover, there exists a range of treatments from which people may choose a particular approach to suit their needs and preferences. Based on this finding, the report's principal recommendation to the American people is to ***seek help if you have a mental health problem or think you have symptoms of mental illness***. The chapter explores opportunities to overcome barriers to implementing the recommendation and to have seeking help lead to effective treatment.

Chapter Conclusions

Chapter 2: The Fundamentals of Mental Health and Mental Illness

The past 25 years have been marked by several discrete, defining trends in the mental health field. These have included:

1. The extraordinary pace and productivity of scientific research on the brain and behavior;
2. The introduction of a range of effective treatments for most mental disorders;
3. A dramatic transformation of our society's approaches to the organization and financing of mental health care; and
4. The emergence of powerful consumer and family movements.

Scientific Research. The brain has emerged as the central focus for studies of mental health and mental illness. New scientific disciplines, technologies, and insights have begun to weave a seamless picture of the way in which the brain mediates the influence of biological, psychological, and social factors on human thought, behavior, and emotion in health and in illness. Molecular and cellular biology and molecular genetics, which are complemented by sophisticated cognitive and behavioral sciences, are preeminent research disciplines in the contemporary neuroscience of mental health. These disciplines are affording unprecedented opportunities for "bottom-up" studies of the brain. This term refers to research that is examining the workings of the brain at the most fundamental levels. Studies focus, for example, on the complex neurochemical activity that occurs within individual nerve cells, or neurons, to process information; on the properties and roles of proteins that are expressed, or produced, by a person's genes; and on the interaction of genes with diverse environmental influences. All of these activities now are understood, with increasing clarity, to underlie learning, memory, the experience of emotion, and, when these processes go awry, the occurrence of mental illness or a mental health problem.

Equally important to the mental health field is "top-down" research; here, as the term suggests, the aim is to understand the broader behavioral context of the brain's cellular and molecular activity and to learn how individual neurons work together in well-delineated neural circuits to perform mental functions.

Effective Treatments. As information accumulates about the basic workings of the brain, it is the task of translational research to transfer new knowledge into clinically relevant questions and targets of research opportunity—to discover, for example, what specific properties of a neural circuit might make it receptive to safer, more effective medications. To elaborate on this example, theories derived from knowledge about basic brain mechanisms are being wedded more closely to brain imaging tools such as functional Magnetic Resonance Imaging (MRI) that can observe actual brain activity. Such a collaboration would permit investigators to monitor the specific protein molecules intended as the "targets" of a new medication to treat a mental illness or, indeed, to determine how to optimize the effect on the brain of the learning achieved through psychotherapy.

In its entirety, the new "integrative neuroscience" of mental health offers a way to circumvent the antiquated split between the mind and the body that historically has hampered mental health research. It also makes it possible to examine scientifically many of the important psychological and behavioral theories regarding normal development and mental illness that have been developed in years past. The unswerving goal of mental health research is to develop and refine clinical treatments as well as preventive interventions that are based on an understanding of specific mechanisms that can contribute to or lead to illness but also can protect and enhance mental health.

Mental health clinical research encompasses studies that involve human participants, conducted, for example, to test the efficacy of a new treatment. A noteworthy feature of contemporary clinical research is the new emphasis being placed on studying the effectiveness of interventions in actual practice settings. Information obtained from such studies increasingly provides the foundation for services research concerned with the cost, cost-effectiveness, and "deliverability" of interventions and the design—including economic considerations—of service delivery systems.

Organization and Financing of Mental Health Care. Another of the defining trends has been the transformation of the mental illness treatment and mental health services landscapes, including increased reliance on primary health care and other human service providers. Today, the U.S. mental health system is multifaceted and complex, comprising the public and private sectors, general health and specialty mental health providers, and social services, housing, criminal justice, and educational agencies. These agencies do not always function in a coordinated manner. Its configuration reflects necessary responses to a broad array of factors including reform movements, financial incentives based on who pays for what kind of services, and advances in care and treatment technology. Although the hybrid system that exists today serves diverse functions well for many people, individuals with the most complex needs and the fewest financial resources often find the system fragmented and difficult to use. A challenge for the Nation in the near-term future is to speed the transfer of new evidence-based treatments and prevention interventions into diverse service delivery settings and systems, while ensuring greater coordination among these settings and systems.

Consumer and Family Movements. The emergence of vital consumer and family movements promises to shape the direction and complexion of mental health programs for many years to come. Although divergent in their historical origins and philosophy, organizations representing consumers and family members have promoted important, often overlapping goals and have invigorated the fields of research as well as treatment and service delivery design. Among the principal goals shared by much of the consumer movement are to overcome stigma and prevent discrimination in policies affecting persons with mental illness; to encourage self-help and a focus on recovery from mental illness; and to draw attention to the special needs associated with a particular disorder or disability, as well as by age or gender or by the racial and cultural identity of those who have mental illness.

Chapter 2 of the report was written to provide background information that would help persons from outside the mental health field better understand topics addressed in subsequent chapters of the report. Although the chapter is meant to serve as a mental health primer, its depth of discussion supports a range of conclusions:

1. The multifaceted complexity of the brain is fully consistent with the fact that it supports all behavior and mental life. Proceeding from an acknowledgment that all psychological experiences are recorded ultimately in the brain and that all psychological phenomena reflect biological processes, the modern neuroscience of mental health offers an enriched understanding of the inseparability of human experience, brain, and mind.
2. Mental functions, which are disturbed in mental disorders, are mediated by the brain. In the process of transforming human experience into physical events, the brain undergoes changes in its cellular structure and function.
3. Few lesions or physiologic abnormalities define the mental disorders, and for the most part their causes remain unknown. Mental disorders, instead, are defined by signs, symptoms, and functional impairments.
4. Diagnoses of mental disorders made using specific criteria are as reliable as those for general medical disorders.
5. About one in five Americans experiences a mental disorder in the course of a year. Approximately 15 percent of all adults who have a mental disorder in one year also experience a co-occurring substance (alcohol or other drug) use disorder, which complicates treatment.
6. A range of treatments of well-documented efficacy exists for most mental disorders. Two broad types of intervention include psychosocial treatments—for example, psychotherapy or counseling—and psychopharmacologic treatments; these often are most effective when combined.
7. In the mental health field, progress in developing preventive interventions has been slow because, for most major mental disorders, there is insufficient understanding about etiology (or causes of illness) and/or there is an inability to alter the *known* etiology of a particular disorder. Still, some successful strategies have emerged in the absence of a full understanding of etiology.
8. About 10 percent of the U.S. adult population use mental health services in the health sector in any year, with another 5 percent seeking such services from social service agencies, schools, or religious or self-help groups. Yet critical gaps exist between those who need service and those who receive service.
9. Gaps also exist between optimally effective treatment and what many individuals receive in actual practice settings.
10. Mental illness and less severe mental health problems must be understood in a social and cultural context, and mental health services must be designed and delivered in a manner that is sensitive to the perspectives and needs of racial and ethnic minorities.
11. The consumer movement has increased the involvement of individuals with mental disorders and their families in mutual support services, consumer-run services, and advocacy. They are powerful agents for changes in service programs and policy.
12. The notion of recovery reflects renewed optimism about the outcomes of mental illness, including that achieved through an individual's own self-care efforts, and the opportunities open to persons with mental illness to participate to the full extent of their interests in the community of their choice.

Mental Health and Mental Illness Across the Lifespan

The Surgeon General's report takes a lifespan approach to its consideration of mental health and mental illness. Three chapters that address, respectively, the periods of childhood and adolescence, adulthood, and later adult life beginning somewhere between ages 55 and 65, capture the contributions of research to the breadth, depth, and vibrancy that characterize all facets of the contemporary mental health field.

The disorders featured in depth in Chapters 3, 4, and 5 were selected on the basis of the frequency with which they occur in our society, and the clinical, societal, and economic burden associated with each. To the extent that data permit, the report takes note of how gender and culture, in addition to age, influence the diagnosis, course, and treatment of mental illness. The chapters also note the changing role of consumers and families, with attention to informal support services (i.e., unpaid services), with which many consumers are comfortable and upon which they depend for information. Persons with mental illness and, often, their families welcome a proliferating array of support services—such as self-help programs, family self-help, crisis services, and advocacy—that help them cope with the isolation, family disruption, and possible loss of employment and housing that may accompany mental disorders. Support services can help to dissipate stigma and to guide patients into formal care as well.

Mental health and mental illness are dynamic, ever-changing phenomena. At any given moment, a person's mental status reflects the sum total of that individual's genetic inheritance and life experiences. The brain interacts with and responds—both in its function and in its very structure—to multiple influences continuously, across every stage of life. At different stages, variability in expression of mental health and mental illness can be very subtle or very pronounced. As an example, the symptoms of separation anxiety are normal in early childhood but are signs of distress in later childhood and beyond. It is all too common for people to appreciate the impact of developmental processes in children, yet not to extend that conceptual understanding to older people. In fact, people continue to develop and change throughout life. Different stages of life are associated with vulnerability to distinct forms of mental and behavioral disorders but also with distinctive capacities for mental health.

Even more than is true for adults, children must be seen in the context of their social environments—that is, family and peer group, as well as that of their larger physical and cultural surroundings. Childhood mental health is expressed in this context, as children proceed along the arc of development. A great deal of contemporary research focuses on developmental processes, with the aim of understanding and predicting the forces that will keep children and adolescents mentally healthy and maintain them on course to become mentally healthy adults. Research also focuses on identifying what factors place some at risk for mental illness and, yet again, what protects some children but not others despite exposure to the *same* risk factors. In addition to studies of normal development and of risk factors, much research focuses on mental disorders in childhood and adolescence and what can be done to prevent or treat these conditions and on the design and operation of service settings best suited to the needs experienced by children.

For about one in five Americans, adulthood—a time for achieving productive vocations and for sustaining close relationships at home and in the community—is interrupted by mental illness. Understanding why and how mental disorders occur in adulthood, often with no apparent portents of illness in earlier years, draws heavily on the full panoply of research conducted under the aegis of the mental health field. In years past, the onset, or occurrence, of mental illness in the adult years, was attributed principally to observable phenomena—for example, the burden of stresses associated with career or family, or the inheritance of a disease viewed to run in a particular family. Such explanations now may appear naive at best. Contemporary studies of the brain and behavior are racing to fill in the picture by elucidating specific neurobiological and genetic mechanisms that are the platform upon which a person's life experiences can either strengthen mental health or lead to mental illness. It now is recognized that factors that influence brain development prenatally may set the stage for a vulnerability to illness that may lie dormant throughout childhood and adolescence. Similarly, no single gene has been found to be responsible for any specific mental disorder; rather, variations in multiple genes contribute to a disruption in healthy brain function that, under certain environmental conditions, results in a mental illness. Moreover, it is now recognized that socioeconomic factors affect individuals' vulnerability to mental illness and mental health problems. Certain demographic and economic groups are more likely than others to experience mental health problems and some mental disorders. Vulnerability alone may not be sufficient to cause a mental disorder; rather, the causes of most mental disorders lie in some combination of genetic and environmental factors, which may be biological or psychosocial.

The fact that many, if not most, people have experienced mental health problems that mimic or even match some of the symptoms of a diagnosable mental disorder tends, ironically, to prompt many people to underestimate the painful, disabling nature of severe mental illness. In fact, schizophrenia, mood disorders such as major depression and bipolar illness, and anxiety often are devastating conditions. Yet relatively few mental illnesses have an unremitting course marked by the most acute manifestations of illness; rather, for reasons that are not yet understood, the symptoms associated with mental illness tend to wax and wane. These patterns pose special challenges to the implementation of treatment plans and the design of service systems that are optimally responsive to an individual's needs during every phase of illness. As this report concludes, enormous strides are being made in diagnosis, treatment, and service delivery, placing the productive and creative possibilities of adulthood within the reach of persons who are encumbered by mental disorders.

Late adulthood is when changes in health status may become more noticeable and the ability to compensate for decrements may become limited. As the brain ages, a person's capacity for certain mental tasks tends to diminish, even as changes in other mental activities prove to be positive and rewarding. Well into late life, the ability to solve novel problems can be enhanced through training in cognitive skills and problem-solving strategies.

The promise of research on mental health promotion notwithstanding, a substantial minority of older people are disabled, often severely, by mental disorders including Alzheimer's disease, major depression, substance abuse, anxiety, and other conditions. In the United States today, the highest rate of suicide—an all-too-common consequence of unrecognized or inappropriately treated depression—is found in older males. This fact underscores the urgency of ensuring that health care provider training properly emphasizes skills required to differentiate accurately the causes of cognitive, emotional, and behavioral symptoms that may, in some instances, rise to the level of mental disorders, and in other instances be expressions of unmet general medical needs.

As the life expectancy of Americans continues to extend, the sheer number—although not necessarily the proportion—of persons experiencing mental disorders of late life will expand, confronting our society with unprecedented challenges in organizing, financing, and delivering effective mental health services for this population. An essential part of the needed societal response will include recognizing and devising innovative ways of supporting the increasingly more prominent role that families are assuming in caring for older, mentally impaired and mentally ill family members.

Chapter 3: Children and Mental Health

1. Childhood is characterized by periods of transition and reorganization, making it critical to assess the mental health of children and adolescents in the context of familial, social, and cultural expectations about age-appropriate thoughts, emotions, and behavior.
2. The range of what is considered "normal" is wide; still, children and adolescents can and do develop mental disorders that are more severe than the "ups and downs" in the usual course of development.
3. Approximately one in five children and adolescents experiences the signs and symptoms of a DSM-IV disorder during the course of a year, but only about 5 percent of all children experience what professionals term "extreme functional impairment."
4. Mental disorders and mental health problems appear in families of all social classes and of all backgrounds. No one is immune. Yet there are children who are at greatest risk by virtue of a broad array of factors. These include physical problems; intellectual disabilities (retardation); low birth weight; family history of mental and addictive disorders; multigenerational poverty; and caregiver separation or abuse and neglect.
5. Preventive interventions have been shown to be effective in reducing the impact of risk factors for

mental disorders and improving social and emotional development by providing, for example, educational programs for young children, parent-education programs, and nurse home visits.

6. A range of efficacious psychosocial and pharmacologic treatments exists for many mental disorders in children, including attention-deficit/hyperactive disorder, depression, and the disruptive disorders.
7. Research is under way to demonstrate the effectiveness of most treatments for children in actual practice settings (as opposed to evidence of "efficacy" in controlled research settings), and significant barriers exist to receipt of treatment.
8. Primary care and the schools are major settings for the potential recognition of mental disorders in children and adolescents, yet trained staff are limited, as are options for referral to specialty care.
9. The multiple problems associated with "serious emotional disturbance" in children and adolescents are best addressed with a "systems" approach in which multiple service sectors work in an organized, collaborative way. Research on the effectiveness of systems of care shows positive results for system outcomes and functional outcomes for children; however, the relationship between changes at the system level and clinical outcomes is still unclear.
10. Families have become essential partners in the delivery of mental health services for children and adolescents.
11. Cultural differences exacerbate the general problems of access to appropriate mental health services. Culturally appropriate services have been designed but are not widely available.

Chapter 4: Adults and Mental Health

1. As individuals move into adulthood, developmental goals focus on productivity and intimacy including pursuit of education, work, leisure, creativity, and personal relationships. Good mental health enables individuals to cope with adversity while pursuing these goals.
2. Untreated, mental disorders can lead to lost productivity, unsuccessful relationships, and significant distress and dysfunction. Mental illness in adults can have a significant and continuing effect on children in their care.
3. Stressful life events or the manifestation of mental illness can disrupt the balance adults seek in life and result in distress and dysfunction. Severe or life-threatening trauma experienced either in childhood or adulthood can further provoke emotional and behavioral reactions that jeopardize mental health.
4. Research has improved our understanding of mental disorders in the adult stage of the life cycle. Anxiety, depression, and schizophrenia, particularly, present special problems in this age group. Anxiety and depression contribute to the high rates of suicide in this population. Schizophrenia is the most persistently disabling condition, especially for young adults, in spite of recovery of function by some individuals in mid to late life.
5. Research has contributed to our ability to recognize, diagnose, and treat each of these conditions effectively in terms of symptom control and behavior management. Medication and other therapies can be independent, combined, or sequenced depending on the individual's diagnosis and personal preference.
6. A new recovery perspective is supported by evidence on rehabilitation and treatment as well as by the personal experiences of consumers.
7. Certain common events of midlife (e.g., divorce or other stressful life events) create mental health problems (not necessarily disorders) that may be addressed through a range of interventions.
8. Care and treatment in the real world of practice do not conform to what research determines is best. For many reasons, at times care is inadequate, but there are models for improving treatment.
9. Substance abuse is a major co-occurring problem for adults with mental disorders. Evidence supports combined treatment, although there are substantial

gaps between what research recommends and what typically is available in communities.

10. Sensitivity to culture, race, gender, disability, poverty, and the need for consumer involvement are important considerations for care and treatment.
11. Barriers of access exist in the organization and financing of services for adults. There are specific problems with Medicare, Medicaid, income supports, housing, and managed care.

Chapter 5: Older Adults and Mental Health

1. Important life tasks remain for individuals as they age. Older individuals continue to learn and contribute to the society, in spite of physiologic changes due to aging and increasing health problems.
2. Continued intellectual, social, and physical activity throughout the life cycle are important for the maintenance of mental health in late life.
3. Stressful life events, such as declining health and/or the loss of mates, family members, or friends often increase with age. However, persistent bereavement or serious depression is not "normal" and should be treated.
4. Normal aging is not characterized by mental or cognitive disorders. Mental or substance use disorders that present alone or co-occur should be recognized and treated as illnesses.
5. Disability due to mental illness in individuals over 65 years old will become a major public health problem in the near future because of demographic changes. In particular, dementia, depression, and schizophrenia, among other conditions, will all present special problems in this age group:
    a. Dementia produces significant dependency and is a leading contributor to the need for costly long-term care in the last years of life;
    b. Depression contributes to the high rates of suicide among males in this population; and
    c. Schizophrenia continues to be disabling in spite of recovery of function by some individuals in mid to late life.
6. There are effective interventions for most mental disorders experienced by older persons (for example, depression and anxiety), and many mental health problems, such as bereavement.
7. Older individuals can benefit from the advances in psychotherapy, medication, and other treatment interventions for mental disorders enjoyed by younger adults, when these interventions are modified for age and health status.
8. Treating older adults with mental disorders accrues other benefits to overall health by improving the interest and ability of individuals to care for themselves and follow their primary care provider's directions and advice, particularly about taking medications.
9. Primary care practitioners are a critical link in identifying and addressing mental disorders in older adults. Opportunities are missed to improve mental health and general medical outcomes when mental illness is underrecognized and undertreated in primary care settings.
10. Barriers to access exist in the organization and financing of services for aging citizens. There are specific problems with Medicare, Medicaid, nursing homes, and managed care.

Chapter 6: Organization and Financing of Mental Health Services

In the United States in the late 20th century, research-based capabilities to identify, treat, and, in some instances, prevent mental disorders is outpacing the capacities of the service system the Nation has in place to deliver mental health care to all who would benefit from it. Approximately 10 percent of children and adults receive mental health services from mental health specialists or general medical providers in a given year. Approximately one in six adults, and one in five children, obtain mental health services either from health care providers, the clergy, social service agencies, or schools in a given year.

Chapter 6 discusses the organization and financing of mental health services. The chapter provides an overview of the current system of mental health services, describing where people get care and how they use services. The chapter then presents information on the costs of care and trends in spending.

Only within recent decades, in the face of concerns about discriminatory policies in mental health financing, have the dynamics of insurance financing become a significant issue in the mental health field. In particular, policies that have emphasized cost containment have ushered in managed care. Intensive research currently is addressing both positive and adverse effects of managed care on access and quality, generating information that will guard against untoward consequences of aggressive cost-containment policies. Inequities in insurance coverage for mental health and general medical care—the product of decades of stigma and discrimination—have prompted efforts to correct them through legislation designed to produce financing changes and create parity. Parity calls for equality between mental health and other health coverage.

1. Epidemiologic surveys indicate that one in five Americans has a mental disorder in any one year.
2. Fifteen percent of the adult population use some form of mental health service during the year. Eight percent have a mental disorder; 7 percent have a mental health problem.
3. Twenty-one percent of children ages 9 to 17 receive mental health services in a year.
4. The U.S. mental health service system is complex and connects many sectors (public–private, specialty–general health, health–social welfare, housing, criminal justice, and education). As a result, care may become organizationally fragmented, creating barriers to access. The system is also financed from many funding streams, adding to the complexity, given sometimes competing incentives between funding sources.
5. In 1996, the direct treatment of mental disorders, substance abuse, and Alzheimer's disease cost the Nation $99 billion; direct costs for mental disorders alone totaled $69 billion. In 1990, indirect costs for mental disorders alone totaled $79 billion.
6. Historically, financial barriers to mental health services have been attributable to a variety of economic forces and concerns (e.g., market failure, adverse selection, moral hazard, and public provision). This has accounted for differential resource allocation rules for financing mental health services.
    a. "Parity" legislation has been a partial solution to this set of problems.
    b. Implementing parity has resulted in negligible cost increases where the care has been managed.
7. In recent years, managed care has begun to introduce dramatic changes into the organization and financing of health and mental health services.
8. Trends indicate that in some segments of the private sector per capita mental health expenditures have declined much faster than they have for other conditions.
9. There is little direct evidence of problems with quality in well-implemented managed care programs. The risk for more impaired populations and children remains a serious concern.
10. An array of quality monitoring and quality improvement mechanisms has been developed, although incentives for their full implementation has yet to emerge. In addition, competition on the basis of quality is only beginning in the managed care industry.
11. There is increasing concern about consumer satisfaction and consumers' rights. A Consumers Bill of Rights has been developed and implemented in Federal Employee Health Benefit Plans, with broader legislation currently pending in the Congress.

Chapter 7: Confidentiality of Mental Health Information: Ethical, Legal, and Policy Issues

In an era in which the confidentiality of all health care information, its accessibility, and its uses are of concern to all Americans, privacy issues are particularly keenly felt in the mental health field. An assurance of confidentiality is understandably critical in individual decisions to seek mental health treatment. Although an extensive legal framework governs confidentiality of consumer-provider interactions, potential problems exist and loom ever larger.

1. People's willingness to seek help is contingent on their confidence that personal revelations of mental distress will not be disclosed without their consent.
2. The U.S. Supreme Court recently has upheld the right to the privacy of these records and the therapist-client relationship.
3. Although confidentiality issues are common to health care in general, there are special concerns for mental health care and mental health care records because of the extremely personal nature of the material shared in treatment.
4. State and Federal laws protect the confidentiality of health care information but are often incomplete because of numerous exceptions which often vary from state to state. Several states have implemented or proposed models for protecting privacy that may serve as a guide to others.
5. States, consumers, and family advocates take differing positions on disclosure of mental health information without consent to family caregivers. In states that allow such disclosure, information provided is usually limited to diagnosis, prognosis, and information regarding treatment, specifically medication.
6. When conducting mental health research, it is in the interest of both the researcher and the individual participant to address informed consent and to obtain certificates of confidentiality before proceeding. Federal regulations require informed consent for research being conducted with Federal funds.
7. New approaches to managing care and information technology threaten to further erode the confidentiality and trust deemed so essential between the direct provider of mental health services and the individual receiving those services. It is important to monitor advances so that confidentiality of records is enhanced, instead of impinged upon, by technology.
8. Until the stigma associated with mental illnesses is addressed, confidentiality of mental health information will continue to be a critical point of concern for payers, providers, and consumers.

Chapter 8: A Vision for the Future—Actions for Mental Health in the New Millennium

The extensive literature that the Surgeon General's report reviews and summarizes leads to the conclusion that ***a range of treatments of documented efficacy exists for most mental disorders***. Moreover, a person may choose a particular approach to suit his or her needs and preferences. Based on this finding, the report's principal recommendation to the American people is to ***seek help if you have a mental health problem or think you have symptoms of a mental disorder***. As noted earlier, stigma interferes with the willingness of many people—even those who have a serious mental illness—to seek help. And, as documented in this report, those who do seek help will all too frequently learn that there are substantial gaps in the availability of state-of-the-art mental health services and barriers to their accessibility. Accordingly, the final chapter of the report goes on to explore opportunities to overcome barriers to implementing the recommendation and to have seeking help lead to effective treatment.

The final chapter identifies the following courses of action.

1. ***Continue to Build the Science Base***: Today, integrative neuroscience and molecular genetics present some of the most exciting basic research opportunities in medical science. A plethora of new pharmacologic agents and psychotherapies for mental disorders afford new treatment opportunities but also challenge the scientific community to develop new approaches to clinical and health services interventions research. Because the vitality and feasibility of clinical research hinges on the willing participation of clinical research volunteers, it is important for society to ensure that concerns about protections for vulnerable research subjects are addressed. Responding to the calls of managed mental and behavioral health care systems for evidence-based interventions will have a much needed and discernible impact on practice. Special effort is required to address pronounced gaps in the mental

health knowledge base. Key among these are the urgent need for evidence which supports strategies for mental health promotion and illness prevention. Additionally, research that explores approaches for reducing risk factors and strengthening protective factors for the prevention of mental illness should be encouraged. As noted throughout the report, high-quality research and the effective services it promotes are a potent weapon against stigma.

2. ***Overcome Stigma***: Powerful and pervasive, stigma prevents people from acknowledging their own mental health problems, much less disclosing them to others. For our Nation to reduce the burden of mental illness, to improve access to care, and to achieve urgently needed knowledge about the brain, mind, and behavior, stigma must no longer be tolerated. Research on brain and behavior that continues to generate ever more effective treatments for mental illnesses is a potent antidote to stigma. The issuance of this Surgeon General's Report on Mental Health seeks to help reduce stigma by dispelling myths about mental illness, by providing accurate knowledge to ensure more informed consumers, and by encouraging help seeking by individuals experiencing mental health problems.
3. ***Improve Public Awareness of Effective Treatment***: Americans are often unaware of the choices they have for effective mental health treatments. In fact, there exists a constellation of several treatments of documented efficacy for most mental disorders. Treatments fall mainly under several broad categories—counseling, psychotherapy, medication therapy, rehabilitation—yet within each category are many more choices. All human services professionals, not just health professionals, have an obligation to be better informed about mental health treatment resources in their communities and should encourage individuals to seek help from any source in which they have confidence.
4. ***Ensure the Supply of Mental Health Services and Providers***: The fundamental components of effective service delivery, which include integrated community-based services, continuity of providers and treatments, family support services (including psychoeducation), and culturally sensitive services, are broadly agreed upon, yet certain of these and other mental health services are in consistently short supply, both regionally and, in some instances, nationally. Because the service system as a whole, as opposed to treatment services considered in isolation, dictates the outcome of recovery-oriented mental health care, it is imperative to expand the supply of effective, evidence-based services throughout the Nation. Key personnel shortages include mental health professionals serving children/adolescents and older people with serious mental disorders and specialists with expertise in cognitive-behavioral therapy and interpersonal therapy, two forms of psychotherapy that research has shown to be effective for several severe mental disorders. For adults and children with less severe conditions, primary health care, the schools, and other human services must be prepared to assess and, at times, to treat individuals who come seeking help.
5. ***Ensure Delivery of State-of-the-Art Treatments***: A wide variety of effective, community-based services, carefully refined through years of research, exist for even the most severe mental illnesses yet are not being translated into community settings. Numerous explanations for the gap between what is known from research and what is practiced beg for innovative strategies to bridge it.
6. ***Tailor Treatment to Age, Gender, Race, and Culture***: Mental illness, no less than mental health, is influenced by age, gender, race, and culture as well as additional facets of diversity that can be found within all of these population groups—for example, physical disability or a person's sexual orientation choices. To be effective, the diagnosis and treatment of mental illness must be tailored to all characteristics that shape a person's image and identity. The consequences of not understanding these influences can be profoundly deleterious. "Culturally competent" services incorporate understanding of racial and ethnic groups, their histories, traditions, beliefs, and value systems. With appropriate training and a fundamental respect for

clients, any mental health professional can provide culturally competent services that reflect sensitivity to individual differences and, at the same time, assign validity to an individual's group identity. Nonetheless, the preference of many members of ethnic and racial minority groups to be treated by mental health professionals of similar background underscores the need to redress the current insufficient supply of mental health professionals who are members of racial and ethnic minority groups.

7. ***Facilitate Entry Into Treatment***: Public and private agencies have an obligation to facilitate entry into mental health care and treatment through the multiple "portals of entry" that exist: primary health care, schools, and the child welfare system. To enhance adherence to treatment, agencies should offer services that are responsive to the needs and preferences of service users and their families. At the same time, some agencies receive inappropriate referrals. For example, an alarming number of children and adults with mental illness are in the criminal justice system inappropriately. Importantly, assuring the small number of individuals with severe mental disorders who pose a threat of danger to themselves or others ready access to adequate and appropriate services promises to reduce significantly the *need* for coercion in the form of involuntary commitment to a hospital and/or certain outpatient treatment requirements that have been legislated in most states and territories. Coercion should not be a substitute for effective care that is sought voluntarily; consensus on this point testifies to the need for research designed to enhance adherence to treatment.
8. ***Reduce Financial Barriers to Treatment***: Concerns about the cost of care—concerns made worse by the disparity in insurance coverage for mental disorders in contrast to other illnesses—are among the foremost reasons why people do not seek needed mental health care. While both access to and use of mental health services increase when benefits for those services are enhanced, preliminary data show that the effectiveness—and, thus, the value—of mental health care also has increased in recent years, while expenditures for services, under managed care, have fallen. Equality between mental health coverage and other health coverage—a concept known as parity—is an affordable and effective objective.

Scope of Coverage of the Report

This report is comprehensive but not exhaustive in its coverage of mental health and mental illness. It considers mental health facets of some conditions which are not always associated with the mental disorders and does not consider all conditions which can be found in classifications of mental disorders such as DSM-IV. The report includes, for example, a discussion of autism in Chapter 3 and provides an extensive section on Alzheimer's disease in Chapter 5. Although DSM-IV lists specific mental disorder criteria for both of these conditions, they often are viewed as being outside the scope of the mental health field. In both cases, mental health professionals are involved in the diagnosis and treatment of these conditions, often characterized by cognitive and behavioral impairments. The developmental disabilities and mental retardation are not discussed except in passing in this report. These conditions were considered to be beyond its scope with a care system all their own and very special needs. The same is generally true for the addictive disorders, such as alcohol and other drug use disorders. The latter, however, co-occur with such frequency with the other mental disorders, which are the focus of this report, that the co-occurrence is discussed throughout. The report covers the epidemiology of addictive disorders and their co-occurrence with other mental disorders as well as the treatment of co-occurring conditions. Brief sections on substance abuse in adolescence and late life also are included in the report.

Preparation of the Report

In September 1997, the Office of the Surgeon General, with the approval of the Secretary of the Department of Health and Human Services, authorized the Substance Abuse and Mental Health Services Administration (SAMHSA) to serve as lead operating division for preparing the first Surgeon General's Report on Mental Health. SAMHSA's Center for Mental Health Services worked in partnership with the National Institute of Mental Health of the National Institutes of Health to develop this report under the guidance of Surgeon General David Satcher. These Federal partners established a Planning Board comprising individuals representing a broad range of expertise in mental health, including academicians, mental health professionals, researchers in neuroscience and service delivery, and self-identified consumers of mental health services and family members of consumers of mental health services. Also included on the Planning Board were individuals representing Federal operating divisions, offices, centers, and institutes and private nonprofit foundations with interests in mental health.

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CHAPTER 2

THE FUNDAMENTALS OF MENTAL HEALTH AND MENTAL ILLNESS

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CHAPTER 2

THE FUNDAMENTALS OF MENTAL HEALTH AND MENTAL ILLNESS

A vast body of research on mental health and, to an even greater extent, on mental illness constitutes the foundation of this Surgeon General's report. To understand and better appreciate the content of the chapters that follow, readers outside the mental health field may desire some background information. Thus, this chapter furnishes a "primer" on topics that the report addresses.

The chapter begins with an overview of research under way today that is focused on the neuroscience of mental health. Modern integrative neuroscience offers a means of linking research on broad "systems level" aspects of brain function with the remarkably detailed tools and findings of molecular biology. The report begins with a discussion of the brain because it is central to what makes us human and provides an understanding of mental health and mental illness. All of human behavior is mediated by the brain. Consider, for example, a memory that most people have from childhood—that of learning to ride a bicycle with the help of a parent or friend. The fear of falling, the anxiety of lack of control, the reassurances of a loved one, and the final liberating experience of mastery and a newly extended universe create an unforgettable combination. For some, the memories are not good ones: falling and being chased by dogs have left marks of anxiety and fear that may last a lifetime. Science is revealing how the skill learning, emotional overtones, and memories of such experiences are put together physically in the brain. The brain and mind are two sides of the same coin. Mind is not possible without the remarkable physical complexity that is built into the brain, but, in addition, the physical complexity of the brain is useless without the sculpting that environment, experience, and thought itself provides. Thus the brain is now known to be physically shaped by contributions from our genes and our experience, working together. This strengthens the view that mental disorders are both caused and can be treated by biological and experiential processes, working together. This understanding has emerged from the breathtaking progress in modern neuroscience that has begun to integrate knowledge from biological and behavioral sciences.

An overview of mental illness follows the section on modern integrative brain science. The section highlights topics including symptoms, diagnosis, epidemiology (i.e., research having to do with the distribution and determinants of mental disorders in population groups, including various racial and ethnic minority groups), and cost, all of which are discussed in greater and more pointed detail in the chapters that follow. Etiology is the study of the origins and causes of disease, and that section reviews research that is seeking to define, with ever greater precision, the causes of mental disorders. As will be seen, etiology research examines fundamental biological, behavioral, and sociocultural processes, as well as a necessarily broad array of life events. The section on development of temperament reveals how mental health science has attempted over much of the past century to understand how biological, psychological, and sociocultural factors meld in health as well as in illness. The chapter then reviews research approaches to the prevention and treatment of mental disorders and provides an overview of mental health services and their delivery. Final sections cover the growing influence on the mental health field of the need for attention to cultural diversity, the importance of the consumer movement, and new optimism about recovery from mental illness—that is, the possibility of recovering one's life.

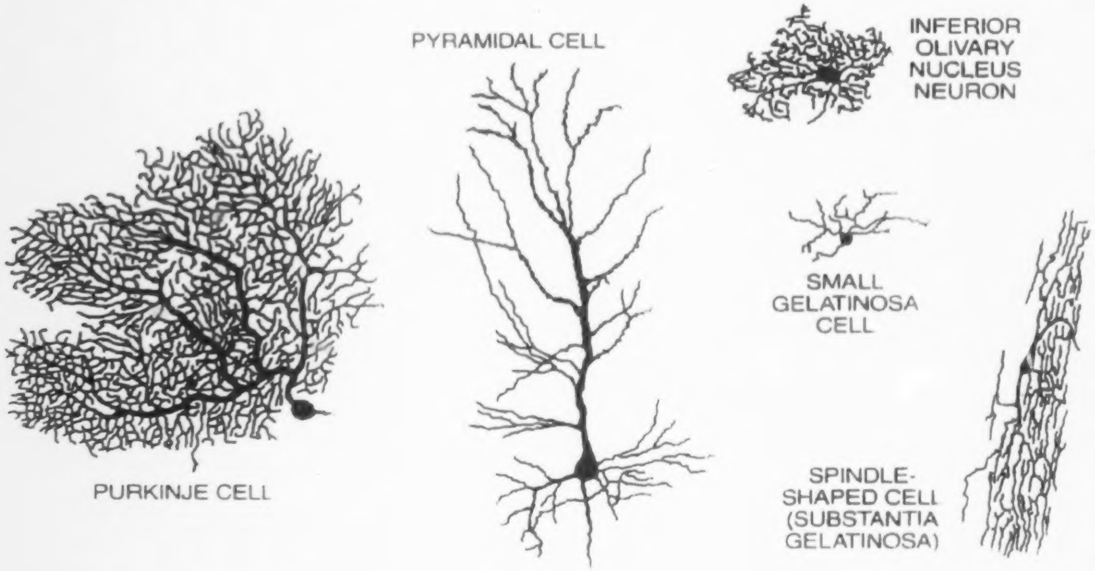
The Neuroscience of Mental Health[1]

Complexity of the Brain I: Structural

As befits the organ of the mind, the human brain is the most complex structure ever investigated by our science. The brain contains approximately 100 billion nerve cells, or neurons, and many more supporting cells, or glia. In and of themselves, the number of cells in this 3-pound organ reveal little of its complexity. Yet most organs in the body are composed of only a handful of cell types; the brain, in contrast, has literally thousands of different kinds of neurons, each distinct in terms of its chemistry, shape, and connections (Figure 2-1 depicts the structural variety of neurons). To illustrate, one careful, recent investigation of a kind of interneuron that is a small local circuit neuron in the retina, called the amacrine cell, found no less than 23 identifiable types.

But this is only the beginning of the brain's complexity.

Figure 2-1. Structural variety of neurons


PYRAMIDAL CELL
INFERIOR OLIVARY NUCLEUS NEURON
SMALL GELATINOSA CELL
PURKINJE CELL
SPINDLE-SHAPED CELL (SUBSTANTIA GELATINOSA)

Source: Fischbach, 1992, p. 53. (Permission granted: Patricia J. Wynne.)

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[1] Special thanks to Steven E. Hyman, M.D., Director, National Institute of Mental Health, and Gerald D. Fischbach, M.D., Director, National Institute of Neurological Diseases and Stroke, for their contributions to this section.

The workings of the brain depend on the ability of nerve cells to communicate with each other. Communication occurs at small, specialized structures called synapses. The synapse typically has two parts. One is a specialized presynaptic structure on a terminal portion of the sending neuron that contains packets of signalling chemicals, or neurotransmitters. The second is a postsynaptic structure on the dendrites of the receiving neuron that has receptors for the neurotransmitter molecules.

The typical neuron has a cell body, which contains the genetic material, and much of the cell's energy-producing machinery. Emanating from the cell body are dendrites, branches that are the most important receptive surface of the cell for communication. The dendrites of neurons can assume a great many shapes and sizes, all relevant to the way in which incoming messages are processed. The output of neurons is carried along what is usually a single branch called the axon. It is down this part of the neuron that signals are transmitted out to the next neuron. At its end, the axon may branch into many terminals. (Figure 2-2.)

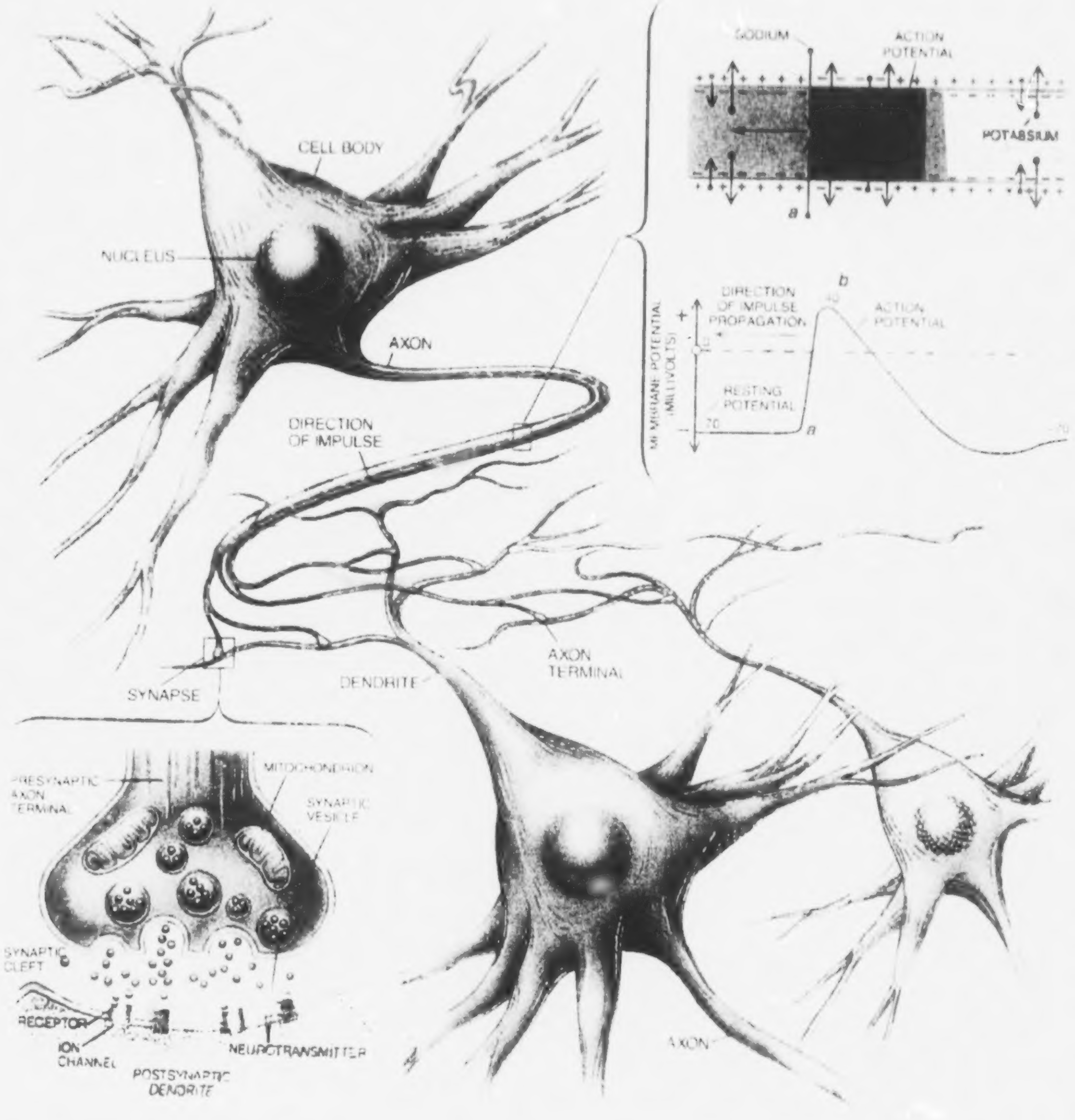
The usual form of communication involves electrical signals that travel within neurons, giving rise to chemical signals that diffuse, or cross, synapses, which in turn give rise to new electrical signals in the postsynaptic neuron. Each neuron, on average, makes more than 1,000 synaptic connections with other neurons. One type of cell—a Purkinje cell—may make between 100,000 and 200,000 connections with other neurons. In aggregate, there may be between 100 trillion and a quadrillion synapses in the brain. These synapses are far from random. Within each region of the brain, there is an exquisite architecture consisting of layers and other anatomic substructures in which synaptic connections are formed. Ultimately, the pattern of synaptic connections gives rise to what are called circuits in the brain. At the integrative level, large- and small-scale circuits are the substrates of behavior and of mental life. One of the most awe-inspiring mysteries of brain science is how neuronal activity within circuits gives rise to behavior and, even, consciousness.

The complexity of the brain is such that a single neuron may be part of more than one circuit. The organization of circuits in the brain reveals that the brain is a massively parallel, distributed information processor. For example, the circuits involved in vision receive information from the retina. After initial processing, these circuits analyze information into different streams, so that there is one stream of information describing what the visual object is, and another stream is concerned with where the object is in space. The information stream having to do with the identity of the object is actually broken down into several more refined parallel streams. One, for example, analyzes shape while another analyzes color. Ultimately, the visual world is resynthesized with information about the tactile world, and the auditory world, with information from memory, and with emotional coloration. The massively parallel design is a great pattern recognizer and very tolerant of failure in individual elements. This is why a brain of neurons is still a better and longer-lasting information processor than a computer.

The specific connectivity of circuits is, to some degree, stereotyped, or set in expected patterns within the brain, leading to the notion that certain places in the brain are specialized for certain functions (Figure 2-3). Thus, the cerebral cortex, the mantle of neurons with its enormous surface area increased by outpouchings, called gyri, and indentations, called sulci, can be functionally subdivided. The back portion of the cerebral cortex (i.e., the occipital lobe), for example, is involved in the initial stages of visual processing. Just behind the central sulcus is the part of the cerebral cortex involved in the processing of tactile information (i.e., parietal lobe). Just in front of the central sulcus is a part of the cerebral cortex involved in motor behavior (frontal lobe). In the front of the brain is a region called the prefrontal cortex, which is involved with some of the highest integrated functions of the human being, including the ability to plan and to integrate cognitive and emotional streams of information.

Beneath the cortex are enormous numbers of axons sheathed in the insulating substance, myelin. This sub-

Figure 2-2. How neurons communicate


SODIUM
ACTION POTENTIAL
POTASSIUM
a
CELL BODY
NUCLEUS
AXON
DIRECTION OF IMPULSE
MEMBRANE POTENTIAL (MILLIVOLTS)
DIRECTION OF IMPULSE PROPAGATION
b
40
ACTION POTENTIAL
0
RESTING POTENTIAL
-70
a
-70
SYNAPSE
DENDRITE
AXON TERMINAL
PRESYNAPTIC AXON TERMINAL
MITOCHONDRION
SYNAPTIC VESICLE
SYNAPTIC CLEFT
RECEPTOR
ION CHANNEL
NEUROTRANSMITTER
POSTSYNAPTIC DENDRITE
AXON

Source: Fischbach, 1992, p. 52. (Permission granted: Tomo Narashima.)

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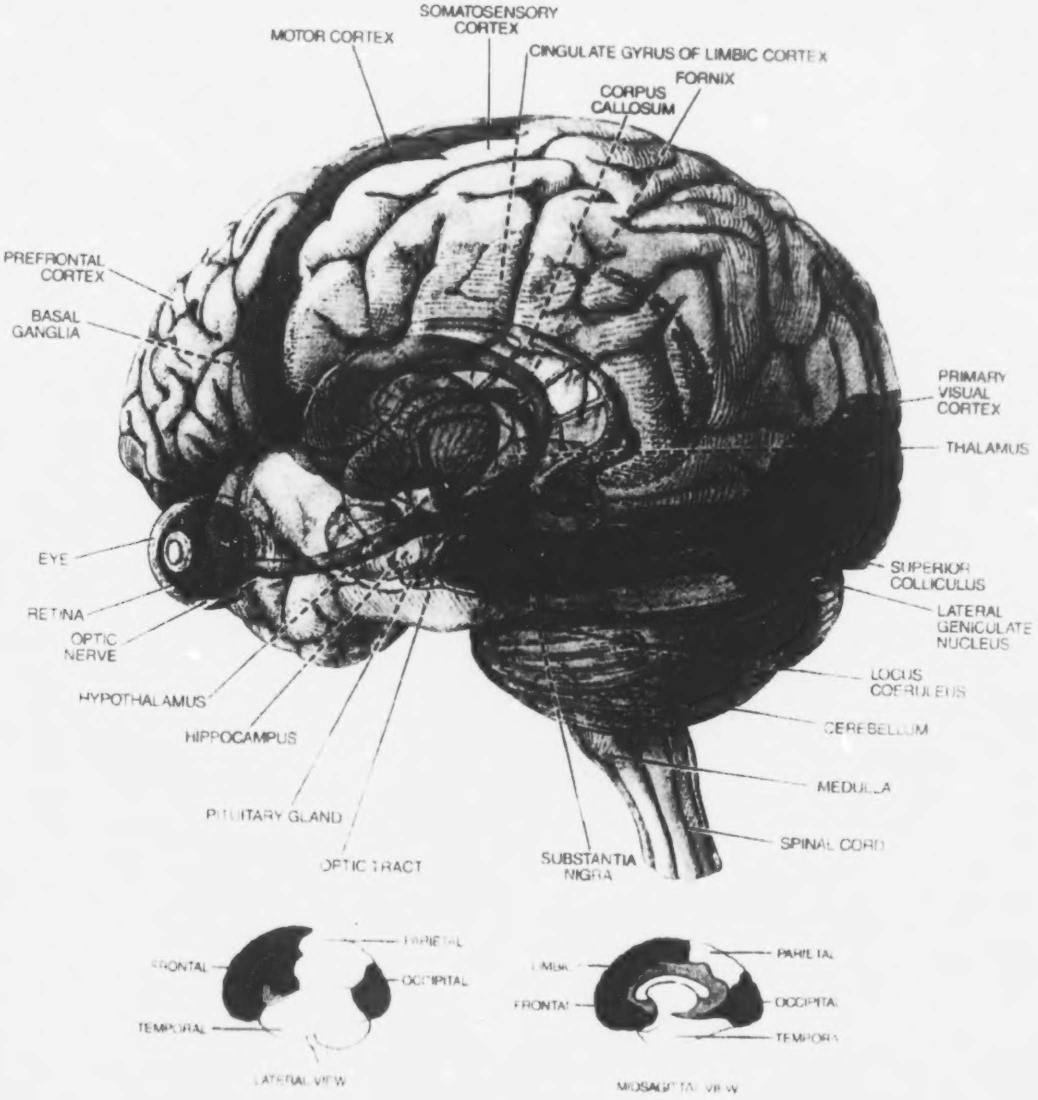
Figure 2-3. The brain: Organ of the mind


SOMATOSENSORY CORTEX
MOTOR CORTEX
CINGULATE GYRUS OF LIMBIC CORTEX
FORNIX
CORPUS CALLOSUM
PREFRONTAL CORTEX
BASAL GANGLIA
PRIMARY VISUAL CORTEX
THALAMUS
EYE
SUPERIOR COLLICULUS
RETINA
LATERAL GENICULATE NUCLEUS
OPTIC NERVE
LOCUS COERULEUS
HYPOTHALAMUS
CEREBELLUM
HIPPOCAMPUS
MEDULLA
PITUITARY GLAND
SPINAL CORD
OPTIC TRACT
SUBSTANTIA NIGRA
PARIETAL
FRONTAL
OCCIPITAL
TEMPORAL
LATERAL VIEW
LIMBIC
PARIETAL
FRONTAL
OCCIPITAL
TEMPORAL
MIDSAGITTAL VIEW

Source: Fischbach, 1992, p. 51. (Permission granted: Carol Donner.)

cortical "white matter," so named because of its appearance on freshly cut brain sections, surrounds deep aggregations of neurons, or "gray matter," which, like the cortex, appears gray because of the presence of neuronal cell bodies. It is within this gray matter that the brain processes information. The white matter is akin to wiring that conveys information from one region to another. Gray matter regions include the basal ganglia, the part of the brain that is involved in the initiation of motion and thus profoundly affected in

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Parkinson's disease, but that is also involved in the integration of motivational states and, thus, a substrate of addictive disorders. Other important gray matter structures in the brain include the amygdala and the hippocampus. The amygdala is involved in the assignment of emotional meaning to events and objects, and it appears to play a special role in aversive, or negative, emotions such as fear. The hippocampus includes, among its many functions, responsibility for initially encoding and consolidating explicit or episodic memories of persons, places, and things.

In summary, the organization of the brain at the cellular level involves many thousands of distinct kinds of neurons. At a higher integrative level, these neurons form circuits for information processing determined by their patterns of synaptic connections. The organization of these parallel distributed circuits results in the specialization of different geographic regions of the brain for different functions. It is important to state at this point, however, that, especially in younger individuals, damage to a particular brain region may yield adaptations that permit circuits spared the damage and, therefore, other regions of the brain, to pick up some of the functions that would otherwise have been lost.

Complexity of the Brain II: Neurochemical

Superimposed on this breathtaking structural complexity is the chemical complexity of the brain. As described above, electrical signals within neurons are converted at synapses into chemical signals which then elicit electrical signals on the other side of the synapse. These chemical signals are molecules called neurotransmitters. There are two major kinds of molecules that serve the function of neurotransmitters: small molecules, some quite well known, with names such as dopamine, serotonin, or norepinephrine, and larger molecules, which are essentially protein chains, called peptides. These include the endogenous opiates, Substance P, and corticotropin releasing factor (CRF), among others. All told, there appear to be more than 100 different neurotransmitters in the brain (Table 2-1 contains a selected list).

A neurotransmitter can elicit a biological effect in the postsynaptic neuron by binding to a protein called a neurotransmitter receptor. Its job is to pass the information contained in the neurotransmitter message from the synapse to the inside of the receiving cell. It appears that almost every known neurotransmitter has more than one different kind of receptor that can confer rather different signals on the receiving neuron. Dopamine has 5 known neurotransmitter receptors; serotonin has at least 14.

Table 2-1. Selected neurotransmitters important in psychopharmacology

Excitatory amino acid
Glutamate

Inhibitory amino acids
Gamma aminobutyric acid
Glycine

Monoamines and related neurotransmitters
Norepinephrine
Dopamine
Serotonin
Histamine
Acetylcholine (quarternary amine)

Purine
Adenosine

Neuropeptides
- ***Opioids***
  - Enkephalins
  - Beta-endorphin
  - Dynorphin
- ***Tachykinin***
  - Substance P
- ***Hypothalamic-releasing factors***
  - Corticotropin-releasing hormone

Although there are many kinds of receptors with many different signaling functions, we can divide most neurotransmitter receptors into two general classes. One class of neurotransmitter receptor is called a ligand-gated channel, where "ligand" simply means a molecule (i.e., a neurotransmitter) that binds to a receptor. When neurotransmitters interact with this kind of receptor, a pore within the receptor molecule itself is opened and positive or negative charges enter the cell. The entry of positive charge may activate additional ion channels that allow more positive charge to enter. At a certain threshold, this causes a cell to fire an action potential—an electrical event that leads ultimately to the release of neurotransmitter. By definition, therefore, receptors that admit positive charge are excitatory neurotransmitter receptors. The classic excitatory neurotransmitter receptors in the brain utilize the excitatory amino acids glutamate and, to a lesser degree, aspartate as neurotransmitters. Conversely, inhibitory neurotransmitters act by permitting negative charges into the cell, taking the cell farther away from firing. The classic inhibitory neurotransmitters in the brain are the amino acids gamma amino butyric acid, or GABA, and, to a lesser degree, glycine.

Most of the other neurotransmitters in the brain, such as dopamine, serotonin, and norepinephrine, and all of the many neuropeptides constitute the second major class. These are neither precisely excitatory nor inhibitory but rather act to produce complex biochemical changes in the receiving cell. Their receptors do not contain intrinsic ion pores but rather interact with signaling proteins, called "G proteins" found inside the cell membrane. These receptors thus are called G protein-linked receptors. The details are less important than understanding the general scheme. Stimulation of G protein-linked receptors alters the way in which receiving neurons can process subsequent signals from glutamate or GABA. To use a metaphor of a musical instrument, if glutamate, the excitatory neurotransmitter, is puffing wind into a flute or clarinet, it is the modulatory neurotransmitters such as dopamine or serotonin that might be seen as playing the keys and, thus, altering the melody via G protein-linked receptors.

The architecture of these systems drives home this point. The precise brain circuits that carry specific information about the world and that are involved in precise point-to-point communication within the brain use excitatory or inhibitory neurotransmission. Examples of such circuits, which are massively parallel, can be found in the visual and auditory cortex. Overlying this pattern of precise, rapid (timing in the range of milliseconds) neurotransmission are the modulatory systems in the brain that use norepinephrine, serotonin, and dopamine. In each case, the neurotransmitter in question is made by a very small number of nerve cells clustered in a limited number of areas in the brain. Of the hundred billion neurons in the brain, only about 500,000, for example, make dopamine—that is, for every 200,000 cells in the brain, only one makes dopamine. Even fewer make norepinephrine. The cell bodies of the dopamine neurons are clustered in a few brain regions, most importantly, regions deep in the brain, in the *midbrain*, called the *substantia nigra*, and the *ventral tegmental area*. Norepinephrine neurons are made in the nucleus *locus coeruleus* even farther down in the brain stem in a structure called the *pons*. Serotonin is made by a somewhat larger number of nuclei but, still, not by many cells. Nuclei called the *raphe nuclei* spread along the brain stem. While each of these neurotransmitters is made by a small number of neurons with clustered cell bodies, each sends its axons branching throughout the brain, so that in each case a very small number of neurons, which largely appear to fire in unison when excited, influence almost the entire brain. This is not the picture of systems that are communicating precise bits of information about the world but rather are intrinsic modulatory systems that act via other G protein-linked receptors to alter the overall responsiveness of the brain. These neurotransmitters are responsible for brain states such as degree of arousal, ability to pay attention, and for putting emotional color or significance on top of cold cognitive information provided by precise glutaminergic circuits. It is no wonder that these modulatory neurotransmitters and their receptors are critical targets of medications used to treat mental disorders—for example, the antidepressant and antipsychotic drugs—and also are the targets of drugs of abuse.

Complexity of the Brain III: Plasticity

The preceding paragraphs have illustrated the chemical and anatomic structure of the brain and, in so doing, provided some picture of its complexity as well as some picture of its function. The crowning complexity of the brain, however, is that it is not static. The brain is always changing. People learn so much and have so many distinct types of memory: conscious, episodic memory of the sort that is encoded initially in the hippocampus; memory of motor programs or procedures that are encoded in the striatum; emotional memories that can initiate physiologic and behaviorally adaptive repertoires encoded, for example, in the amygdala; and many other kinds. Every time a person learns something new, whether it is conscious or unconscious, that experience alters the structure of the brain. Thus, neurotransmission in itself not only contains current information but alters subsequent neurotransmission if it occurs with the right intensity and the right pattern. Experience that is salient enough to cause memory creates new synaptic connections, prunes away old ones, and strengthens or weakens existing ones. Similarly, experiences as diverse as stress, substance abuse, or disease can kill neurons, and current data suggest that new neurons continue to develop even in adult brains, where they help to incorporate new memories. The end result is that information is now routed over an altered circuit. Many of these changes are long-lived, even permanent. It is in this way that a person can look back 10 or 20 or 50 years and remember family, a home or school room, or friends. The general theme is that to really understand the kind of memory—indeed, any brain function—one must think at least at two levels: one, the level of molecular and cellular alterations that are responsible for remodeling synapses, and, two, the level of information content and behavior which circuits and synapses serve.

To summarize this section, scientists are truly beginning to learn about the structure and function of the brain. Its awe-inspiring complexity is fully consistent with the fact that it supports all behavior and mental life. Implied in the foregoing, is the fact that brains are built not only by genes—and again, it is the lion's share of the 80,000 or so human genes that are involved in building a structure so complex as the brain. Genes are not by themselves the whole story. Brains are built and changed through life through the interaction of genes with environment, including experience. It is true that a set of genes might create repetitive multiples of one type of unit, yet the brain appears far more complex than that. It stands to reason that if 50,000 or 60,000 genes are involved in building a brain that may have 100 trillion or a quadrillion synapses, additional information is needed, and that information comes from the environment. It is this fundamental realization that is beginning to permit an understanding of how treatment of mental disorders works—whether in the form of a somatic intervention such as a medication, or a psychological "talk" therapy—by actually changing the brain.

Imaging the Brain

There are many exciting developments in brain science. Of great relevance to the study of mental function and mental illness is the ability to image the activity of the living human brain with technologies developed in recent decades, such as positron emission tomography scanning or functional magnetic resonance imaging. Such approaches can exploit surrogates of neuronal firing such as blood flow and blood oxygenation to provide maps of activity. As science learns more about brain circuitry and learns more from cognitive and affective neuroscience about how to activate and examine the function of particular brain circuits, differences between health and illness in the function of particular circuits certainly will become evident. We will be able to see the action of psychotropic drugs and, perhaps most exciting, we will be able to see the impact of that special kind of learning called psychotherapy, which works after all because it works on the brain.

Different brain chemicals, brain receptors, and brain structures will come up in the discussion of particular illnesses throughout this document. This section is meant to provide a panoramic, not a detailed, introduction and also to provide certain overarching lessons. When something is referred to as biological or brain-based, that is not shorthand for saying it is genetic and, thus, predetermined; similarly, references to "psychological" or even "social" phenomena do not exclude biological processes. The brain is the great integrator, bringing together genes and environment. The study of the brain requires reducing problems initially to bite-sized bits that will allow investigators to learn something, but ultimately, the agenda of neuroscience is not reductionist; the goal is to understand behavior, not to put blinders on and try to explain it away. As the foregoing discussion illustrates, the brain also is complex. Thus, having a disease that affects one or even many critical circuits does not overthrow, except in extreme cases, such as advanced Alzheimer's disease, all aspects of a person. Typically, people retain their personality and, in most cases, their ability to take responsibility for themselves.

In retrospect, early biological models of the mind seem impoverished and deterministic—for example, models that held that "levels" of a neurotransmitter such as serotonin in the brain were the principal influence on whether one was depressed or aggressive. Neuroscience is far beyond that now, working to integrate information coming "bottom-up" from genes and molecules and cells, with information flowing "top-down" from interactions with the environment and experience to the internal workings of the mind and its neuronal circuits. Ultimately, however, the goal is not only human self-understanding. In knowing eventually precisely what goes wrong in what circuits and what synapses and with what chemical signals, the hope is to develop treatments with greater effectiveness and with fewer side effects. Indeed, as the following chapters indicate, the hope is for cures and ultimately for prevention. There is every reason to hope that as our science progresses, we will achieve those goals.

Overview of Mental Illness

Mental illness is a term rooted in history that refers collectively to all of the diagnosable mental disorders. Mental disorders are characterized by abnormalities in cognition, emotion or mood, or the highest integrative aspects of behavior, such as social interactions or planning of future activities. These mental functions are all mediated by the brain. It is, in fact, a core tenet of modern science that behavior and our subjective mental lives reflect the overall workings of the brain. Thus, symptoms related to behavior or our mental lives clearly reflect variations or abnormalities in brain function. On the more difficult side of the ledger are the terms disorder, disease, or illness. There can be no doubt that an individual with schizophrenia is seriously ill, but for other mental disorders such as depression or attention-deficit/hyperactivity disorder, the signs and symptoms exist on a continuum and there is no bright line separating health from illness, distress from disease. Moreover, the manifestations of mental disorders vary with age, gender, race, and culture. The thresholds of mental illness or disorder have, indeed, been set by convention, but the fact is that this gray zone is no different from any other area of medicine. Ten years ago a serum cholesterol of 200 was considered normal. Today, this same number alarms some physicians and may lead to treatment. Perhaps every adult in the United States has some atherosclerosis, but at what point does this move along a continuum from normal into the realm of illness? Ultimately, the dividing line has to do with severity of symptoms, duration, and functional impairment.

Despite the existence of a gray zone between health and illness, science can study the mechanisms by which illness occurs. Indeed, understanding mood regulation and its abnormalities, for example, proceeds independently from any set of diagnostic clinical criteria. Family studies, molecular genetics strategies, epidemiology, and the tools of clinical investigation tailored to specific populations are being used to investigate the mechanisms of mental illness. Specific manifestations of mental illness will be covered in succeeding pages.

This overview of mental illness focuses on those features of the disease process that are most common and characteristic of these disorders. The chapters that follow will present specific details about major categories of mental disorders that occur across the life span. The purpose here is to provide a framework upon which subsequent discussions of specific disorders can rest. The section leads with a descriptive overview of the cardinal manifestations, signs, and symptoms of mental disorders. It then describes how mental disorders are diagnosed and classified and provides an overview of the epidemiology and societal burden of mental disorders.

Manifestations of Mental Illness

Persons suffering from any of the severe mental disorders present with a variety of symptoms that may include inappropriate anxiety, disturbances of thought and perception, dysregulation of mood, and cognitive dysfunction. Many of these symptoms may be relatively specific to a particular diagnosis or cultural influence. For example, disturbances of thought and perception (psychosis) are most commonly associated with schizophrenia. Similarly, severe disturbances in expression of affect and regulation of mood are most commonly seen in depression and bipolar disorder. However, it is not uncommon to see psychotic symptoms in patients diagnosed with mood disorders or to see mood-related symptoms in patients diagnosed with schizophrenia. Symptoms associated with mood, anxiety, thought process, or cognition may occur in any patient at some point during his or her illness.

Anxiety

Anxiety is one of the most readily accessible and easily understood of the major symptoms of mental disorders. Each of us encounters anxiety in many forms throughout the course of our routine activities. It may often take the concrete form of intense fear experienced in response to an immediately threatening experience such as narrowly avoiding a traffic accident. Experiences like this are typically accompanied by strong emotional responses of fear and dread as well as physical signs of anxiety such as rapid heart beat and perspiration. Some of the more common signs and symptoms of anxiety are listed in Table 2-2. Anxiety is aroused most intensely by immediate threats to one's safety, but it also occurs commonly in response to dangers that are relatively remote or abstract. Intense anxiety may also result from situations that one can only vaguely imagine or anticipate.

Anxiety has evolved as a vitally important physiological response to dangerous situations that prepares one to evade or confront a threat in the environment. The appropriate regulation of anxiety is critical to the survival of virtually every higher organism in every environment. However, the mechanisms that regulate anxiety may break down in a wide variety of circumstances, leading to excessive or inappropriate expression of anxiety. Specific examples include phobias, panic attacks, and generalized anxiety. In phobias, high-level anxiety is aroused by specific situations or objects that may range from concrete entities such as snakes, to complex circumstances such as social interactions or public speaking. Panic attacks are brief and very intense episodes of anxiety that often occur without a precipitating event or stimulus. Generalized anxiety represents a more diffuse and nonspecific kind of anxiety that is most often experienced as excessive worrying, restlessness, and tension occurring with a chronic and sustained pattern. In each case, an anxiety disorder may be said to exist if the anxiety experienced is disproportionate to the circumstance, is difficult for the individual to control, or interferes with normal functioning.

Table 2-2. Common signs of acute anxiety

- Feelings of fear or dread
- Trembling, restlessness, and muscle tension
- Rapid heart rate
- Lightheadedness or dizziness
- Perspiration
- Cold hands/feet
- Shortness of breath

In addition to these common manifestations of anxiety, obsessive-compulsive disorder and post-traumatic stress disorder are generally believed to be related to the anxiety disorders. The specific clinical features of these disorders will be described more fully in the following chapters; however, their relationship to anxiety warrants mention in the present context. In the case of obsessive-compulsive disorder, individuals experience a high level of anxiety that drives their obsessional thinking or compulsive behaviors. When such an individual fails to carry out a repetitive

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behavior such as hand washing or checking, there is an experience of severe anxiety. Thus while the outward manifestations of obsessive-compulsive disorder may seem to be related to other anxiety disorders, there appears to be a strong component of abnormal regulation of anxiety underlying this disorder. Post-traumatic stress disorder is produced by an intense and overwhelmingly fearful event that is often life-threatening in nature. The characteristic symptoms that result from such a traumatic event include the persistent reexperience of the event in dreams and memories, persistent avoidance of stimuli associated with the event, and increased arousal.

Psychosis

Disturbances of perception and thought process fall into a broad category of symptoms referred to as psychosis. The threshold for determining whether thought is impaired varies somewhat with the cultural context. Like anxiety, psychotic symptoms may occur in a wide variety of mental disorders. They are most characteristically associated with schizophrenia, but psychotic symptoms can also occur in severe mood disorders.

One of the most common groups of symptoms that result from disordered processing and interpretation of sensory information are the hallucinations. Hallucinations are said to occur when an individual experiences a sensory impression that has no basis in reality. This impression could involve any of the sensory modalities. Thus hallucinations may be auditory, olfactory, gustatory, kinesthetic, tactile, or visual. For example, auditory hallucinations frequently involve the impression that one is hearing a voice. In each case, the sensory impression is falsely experienced as real.

A more complex group of symptoms resulting from disordered interpretation of information consists of delusions. A delusion is a false belief that an individual holds despite evidence to the contrary. A common example is paranoia, in which a person has delusional beliefs that others are trying to harm him or her. Attempts to persuade the person that these beliefs are unfounded typically fail and may even result in the further entrenchment of the beliefs.

Hallucinations and delusions are among the most commonly observed psychotic symptoms. A list of other symptoms seen in psychotic illnesses such as schizophrenia appears in Table 2-3. Symptoms of schizophrenia are divided into two broad classes: *positive* symptoms and *negative* symptoms. Positive symptoms generally involve the experience of something in consciousness that should not normally be present. For example, hallucinations and delusions represent perceptions or beliefs that should not normally be experienced. In addition to hallucinations and delusions, patients with psychotic disorders such as schizophrenia frequently have marked disturbances in the logical process of their thoughts. Specifically, psychotic thought processes are characteristically loose, disorganized, illogical, or bizarre. These disturbances in thought process frequently produce observable patterns of behavior that are also disorganized and bizarre. The severe disturbances of thought content and process that comprise the positive symptoms often are the most recognizable and striking features of psychotic disorders such as schizophrenia or manic depressive illness.

Table 2-3. Common manifestations of schizophrenia

Positive Symptoms
• Hallucinations
• Delusions
• Disorganized thoughts and behaviors
• Loose or illogical thoughts
• Agitation
Negative Symptoms
• Flat or blunted affect
• Concrete thoughts
• Anhedonia (inability to experience pleasure)
• Poor motivation, spontaneity, and initiative

However, in addition to positive symptoms, patients with schizophrenia and other psychoses

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have been noted to exhibit major deficits in motivation and spontaneity that are referred to as negative symptoms. While positive symptoms represent the presence of something not normally experienced, negative symptoms reflect the absence of thoughts and behaviors that would otherwise be expected. Concreteness of thought represents impairment in the ability to think abstractly. Blunting of affect refers to a general reduction in the ability to express emotion. Motivational failure and inability to initiate activities represent a major source of long-term disability in schizophrenia. Anhedonia reflects a deficit in the ability to experience pleasure and to react appropriately to pleasurable situations. Positive symptoms such as hallucinations are responsible for much of the acute distress associated with schizophrenia, but negative symptoms appear to be responsible for much of the chronic and long-term disability associated with the disorder.

The psychotic symptoms represent manifestations of disturbances in the flow, processing, and interpretation of information in the central nervous system. They seem to share an underlying commonality of mechanism, insofar as they tend to respond as a group to specific pharmacological interventions. However, much remains to be learned about the brain mechanisms that lead to psychosis.

Disturbances of Mood

Most of us have an immediate and intuitive understanding of the notion of mood. We readily comprehend what it means to feel sad or happy. These concepts are nonetheless very difficult to formulate in a scientifically precise and quantifiable way; the challenge is greater given the cultural differences that are associated with the expression of mood. In turn, disorders that impact on the regulation of mood are relatively difficult to define and to approach in a quantitative manner. Nevertheless, dysregulation of mood and the expression of mood, or affect, represent a major category among mental disorders.

Disturbances of mood characteristically manifest themselves as a sustained feeling of sadness or sustained elevation of mood. As with anxiety and psychosis, disturbances of mood may occur in a variety of patterns associated with different mental disorders. The disorder most closely associated with persistent sadness is major depression, while that associated with sustained elevation or fluctuation of mood is bipolar disorder. The most common signs of these mood disorders are listed in Table 2-4. Along with the prevailing feelings of sadness or elation, disorders of mood are associated with a host of related symptoms that include disturbances in appetite, sleep patterns, energy level, concentration, and memory.

Table 2-4. Common signs of mood disorders

Symptoms Commonly Associated With Depression

- Persistent sadness or despair
- Insomnia (sometimes hypersomnia)
- Decreased appetite
- Psychomotor retardation
- Anhedonia (inability to experience pleasure)
- Irritability
- Apathy, poor motivation, social withdrawal
- Hopelessness
- Poor self-esteem, feelings of helplessness
- Suicidal ideation

Symptoms Commonly Associated With Mania

- Persistently elevated or euphoric mood
- Grandiosity (inappropriately high self-esteem)
- Psychomotor agitation
- Decreased sleep
- Racing thoughts and distractibility
- Poor judgment and impaired impulse control
- Rapid or pressured speech

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It is not known why diverse functions such as sleep and appetite should be altered in disorders of mood. However, depression and mania are typically associated with characteristic changes in these basic functions. Mood appears to represent a complex group of behaviors and responses that undergo precise and tightly controlled regulation. Higher organisms that must adapt to changing environments depend on optimal control of basic functions such as sleep, appetite, sex, and physical activity. This regulation must adapt to diurnal and seasonal changes in the environment. In addition, more complex behaviors such as exploration, aggression, and social interaction must also undergo a similar, perhaps closely linked, regulation. In humans, these complex behaviors and their regulation are believed to be associated with the expression of mood. A depressed mood appears to reflect a kind of global damping of these functions, while a manic state may result from an excessive activation of these same functions. The mechanisms underlying the diverse changes associated with the mood disorders are largely unknown, but their appearance as clusters in specific disorders along with their collective response to specific therapeutics suggests a common mechanistic basis.

Disturbances of Cognition

Cognitive function refers to the general ability to organize, process, and recall information. Cognitive tasks may be subdivided into a large number of more specific functions depending on the nature of the information remembered and the circumstances of its recall. In addition, there are many functions commonly associated with cognition such as the ability to execute complex sequences of tasks. Disturbances of cognitive function may occur in a variety of disorders. Progressive deterioration of cognitive function is referred to as dementia. Dementia may be caused by a number of specific conditions including Alzheimer's disease (to be discussed in subsequent chapters). Impairment of cognitive function may also occur in other mental disorders such as depression. It is not uncommon to find profound disturbances of cognition in patients suffering from severe mood disturbances. More recently, cognitive deficits have been reported in schizophrenia and now have become a major new topic of research. Lastly, cognitive impairment frequently occurs in a host of chemical, metabolic, and infectious diseases that exert an impact on the brain.

The manifestations of cognitive impairment can vary across an extremely wide range, depending on severity. Short-term memory is one of the earliest functions to be affected and, as severity increases, retrieval of more remote memories becomes more difficult. Attention, concentration, and higher intellectual functions can be impaired as the underlying disease process progresses. Language difficulties range from mild word-finding problems to complete inability to comprehend or use language. Functional impairments associated with cognitive deficits can markedly interfere with the ability to perform activities of daily living such as dressing and bathing.

Other Symptoms

Anxiety, psychosis, mood disturbances, and cognitive impairments are among the most common and disabling manifestations of mental disorders. It is important, however, to appreciate that mental disorders leave no aspect of human experience untouched. It is beyond the scope of the present chapter to detail the full spectrum of presentations of mental disorders. Other common manifestations include, for example, somatic or other physical symptoms and impairment of impulse control. Many of these issues will be touched upon in subsequent chapters with reference to specific disorders.

Diagnosis of Mental Illness

The foregoing discussion has suggested that the manifestations of mental disorders fall into a number of distinct categories such as anxiety, psychosis, mood disturbance, and cognitive deficits. These categories are broad, heterogeneous, and somewhat overlapping. Moreover, any particular patient may manifest symptoms from more than one of these categories. This is not unexpected, given the highly complex interactions that take place among the neurobiological and behavioral substrates that produce these symptoms. Despite these confounding difficulties, a systematic approach to the classification and diagnosis of mental illness has been developed. Diagnosis is essential in all areas of health for shaping treatment and supportive care, establishing a prognosis, and preventing related disability. Diagnosis also serves as shorthand to enhance communication, research, surveillance, and reimbursement.

The diagnosis of mental disorders is often believed to be more difficult than diagnosis of somatic, or general medical, disorders, since there is no definitive lesion, laboratory test, or abnormality in brain tissue that can identify the illness. The diagnosis of mental disorders must rest with the patients' reports of the intensity and duration of symptoms, signs from their mental status examination, and clinician observation of their behavior including functional impairment. These clues are grouped together by the clinician into recognizable patterns known as syndromes. When the syndrome meets all the criteria for a diagnosis, it constitutes a mental disorder. Most mental health conditions are referred to as disorders, rather than as diseases, because diagnosis rests on clinical criteria. The term "disease" generally is reserved for conditions with known pathology (detectable physical change). The term "disorder," on the other hand, is reserved for clusters of symptoms and signs associated with distress and disability (i.e., impairment of functioning), yet whose pathology and etiology are unknown.

The standard manual used for diagnosis of mental disorders in the United States is the *Diagnostic and Statistical Manual of Mental Disorders*. Most recently revised in 1994, this manual now is in its fourth edition (American Psychiatric Association, 1994, hereinafter cited in this report as DSM-IV). The first edition was published in 1952 by the American Psychiatric Association; subsequent revisions, which were made on the basis of field trials, analysis of data sets, and systematic reviews of the research literature, have sought to gain greater objectivity, diagnostic precision, and reliability. DSM-IV organizes mental disorders into 16 major diagnostic classes listed in Table 2-5. For each disorder within a diagnostic class, DSM-IV enumerates specific criteria for making the diagnosis. DSM-IV also lists diagnostic "subtypes" for some disorders. A subtype is a subgroup within a diagnosis that confers greater specificity. DSM-IV is descriptive in its listing of symptoms and does not take a position about underlying causation.

Table 2-5. Major Diagnostic Classes of Mental Disorders (DSM-IV)

Disorders usually first diagnosed in infancy, childhood, or adolescence
Delerium, dementia, and amnestic and other cognitive disorders
Mental disorders due to a general medical condition
Substance-related disorders
Schizophrenia and other psychotic disorders
Mood disorders
Anxiety disorders
Somatoform disorders
Factitious disorders
Dissociative disorders
Sexual and gender identity disorders
Eating disorders
Sleep disorders
Impulse-control disorders
Adjustment disorders
Personality disorders

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DSM-IV and its predecessors[2] represent a unique approach to diagnosis by a professional field. No other sphere of health care has created such an extensive compendium of all of its disorders with explicit diagnostic criteria. The World Health Organization's *International Classification of Diseases* (10th edition, 1992) is a valuable compendium of all diseases. Its mental health categories are expanded upon in DSM-IV. The *International Classification of Diseases* (ICD) is the official classification for mortality and morbidity statistics for all signatories to theU.N. Charter establishing the World Health Organization. ICD-9CM (9th edition, Clinical Modification, 1991) is still the official classification for the Health Care Financing Administration.

Knowledge about diagnosis continues to evolve. Evolution in the diagnosis of mental disorders generally reflects greater understanding of disorders as well as the influence of social norms. Years ago, for instance, addiction to tobacco was not viewed as a disorder, but today it falls under the category of "Substance-Related Disorders." Although DSM-IV strives to cover all populations, it is not without limitations. The difficulties encountered in diagnosing mental disorders in children, older persons, and racial and ethnic minority groups are discussed later in this chapter and throughout this report. Diagnosis rests on clinician judgment about whether clients' symptom patterns and impairments of functioning meet diagnostic criteria. Cultural differences in emotional expression and social behavior can be misinterpreted as "impaired" if clinicians are not sensitive to the cultural context and meaning of exhibited symptoms, a topic discussed later in this chapter in Overview of Cultural Diversity and Mental Health Services.

Epidemiology of Mental Illness

Few families in the United States are untouched by mental illness. Determining just how many people have mental illness is one of the many purposes of the field of epidemiology. Epidemiology is the study of patterns of disease in the population. Among the key terms of this discipline, encountered throughout this report, are *incidence*, which refers to new cases of a condition which occur during a specified period of time, and *prevalence*, which refers to cases (i.e., new and existing) of a condition observed at a point in time or during a period of time. According to current epidemiological estimates, at least one in five people has a diagnosable mental disorder during the course of a year (i.e., 1-year prevalence).

Epidemiological estimates have shifted over time because of changes in the definitions and diagnosis of mental health and mental illness. In the early 1950s, the rates of mental illness estimated by epidemiologists were far higher than those of today. One study, for example, found 81.5 percent of the population of Manhattan, New York, to have had signs and symptoms of mental distress (Srole, 1962). This led the authors of the study to conclude that mental illness was widespread. However, other studies began to find *lower* rates when they used more restrictive definitions that reflected more contemporary views about mental illness. Instead of classifying anyone with signs and symptoms as being mentally ill, this more recent line of epidemiological research only identified people as mentally ill if they had a *cluster* of signs and symptoms that, when taken together, impaired people's ability to function (Pasamanick, 1959; Weissman et al., 1978). By 1978, the President's Commission on Mental Health (1978) concluded conservatively that the annual prevalence of specific mental disorders in the United States was about 15 percent. This figure comports with recent estimates of the extent of mental illness in the population. Even as this figure has become more sharply delineated, the older and larger estimates underscore the magnitude of mental distress in the population, which this report refers to as "mental health problems."

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[2] DSM-I (American Psychiatric Association, 1952), DSM-II (American Psychiatric Association, 1968), DSM-III (American Psychiatric Association, 1979), and DSM-III-R (American Psychiatric Association, 1987).

Adults

The current prevalence estimate is that about 20 percent of the U.S. population are affected by mental disorders during a given year. This estimate comes from two epidemiologic surveys: the Epidemiologic Catchment Area (ECA) study of the early 1980s and the National Comorbidity Survey (NCS) of the early 1990s. Those surveys defined mental illness according to the prevailing editions of the *Diagnostic and Statistical Manual of Mental Disorders* (i.e., DSM-III and DSM-III-R). The surveys estimate that during a 1-year period, 22 to 23 percent of the U.S. adult population—or 44 million people—have diagnosable mental disorders, according to reliable, established criteria. In general, 19 percent of the adult U.S. population have a mental disorder alone (in 1 year); 3 percent have both mental and addictive disorders; and 6 percent have addictive disorders alone.[3] Consequently, about 28 to 30 percent of the population have either a mental *or* addictive disorder (Regier et al., 1993b; Kessler et al., 1994). Table 2-6 summarizes the results synthesized from these two large national surveys.

Individuals with co-occurring disorders (about 3 percent of the population in 1 year) are more likely to experience a chronic course and to utilize services than are those with either type of disorder alone. Clinicians, program developers, and policymakers need to be aware of these high rates of comorbidity—about 15 percent of those with a mental disorder in 1 year (Regier et al., 1993a; Kessler et al., 1996).

Based on data on functional impairment, it is estimated that 9 percent of all U.S. adults have the mental disorders listed in Table 2-6 *and* experience some significant functional impairment (National Advisory Mental Health Council [NAMHC], 1993). Most (7 percent of adults) have disorders that persist for at least 1 year (Regier et al., 1993b; Regier et al., in press). A subpopulation of 5.4 percent of adults is considered to have a "serious" mental illness (SMI) (Kessler et al., 1996). Serious mental illness is a term defined by Federal regulations that generally applies to mental disorders that interfere with some area of social functioning. About half of those with SMI (or 2.6 percent of all adults) were identified as being even more seriously affected, that is, by having "severe and persistent" mental illness (SPMI) (NAMHC, 1993; Kessler et al., 1996). This category includes schizophrenia, bipolar disorder, other severe forms of depression, panic disorder, and obsessive-compulsive disorder. These disorders and the problems faced by these special populations with SMI and SPMI are described further in subsequent chapters. Among those most severely disabled are the approximately 0.5 percent of the population who receive disability benefits for mental health-related reasons from the Social Security Administration (NAMHC, 1993).

Children and Adolescents

The annual prevalence of mental disorders in children and adolescents is not as well documented as that for adults. About 20 percent of children are estimated to have mental disorders with at least mild functional impairment (see Table 2-7). Federal regulations also define a sub-population of children and adolescents with more severe functional limitations, known as "serious emotional disturbance" (SED).[4] Children and adolescents with SED number approximately 5 to 9 percent of children ages 9 to 17 (Friedman et al., 1996b).

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[3] Although addictive disorders are included as mental disorders in the DSM classification system, the ECA and NCS distinguish between addictive disorders and (all other) mental disorders. Epidemiologic data in this report follow that convention.

[4] The term "serious emotional disturbance" is used in a variety of Federal statutes in reference to children under the age of 18 with a diagnosable mental health problem that severely disrupts their ability to function socially, academically, and emotionally. The term does not signify any particular diagnosis; rather, it is a legal term that triggers a host of mandated services to meet the needs of these children.

Table 2-6. Best estimate 1-year prevalence rates based on ECA and NCS, ages 18–54

	ECA Prevalence (%)	NCS Prevalence (%)	Best Estimate ** (%)
Any Anxiety Disorder	13.1	18.7	16.4
Simple Phobia	8.3	8.6	8.3
Social Phobia	2.0	7.4	2.0
Agoraphobia	4.9	3.7	4.9
GAD	(1.5)*	3.4	3.4
Panic Disorder	1.6	2.2	1.6
OCD	2.4	(0.9)*	2.4
PTSD	(1.9)*	3.6	3.6
Any Mood Disorder	7.1	11.1	7.1
MD Episode	6.5	10.1	6.5
Unipolar MD	5.3	8.9	5.3
Dysthymia	1.6	2.5	1.6
Bipolar I	1.1	1.3	1.1
Bipolar II	0.6	0.2	0.6
Schizophrenia	1.3	—	1.3
Nonaffective Psychosis	—	0.2	0.2
Somatization	0.2	—	0.2
ASP	2.1	—	2.1
Anorexia Nervosa	0.1	—	0.1
Severe Cognitive Impairment	1.2	—	1.2
Any Disorder	19.5	23.4	21.0

*Numbers in parentheses indicate the prevalence of the disorder without any comorbidity. These rates were calculated using the NCS data for GAD and PTSD, and the ECA data for OCD. The rates were not used in calculating the any anxiety disorder and any disorder totals for the ECA and NCS columns. The unduplicated GAD and PTSD rates were added to the best estimate total for any anxiety disorder (3.3%) and any disorder (1.5%).

**In developing best-estimate 1-year prevalence rates from the two studies, a conservative procedure was followed that had previously been used in an independent scientific analysis comparing these two data sets (Andrews, 1995). For any mood disorder and any anxiety disorder, the lower estimate of the two surveys was selected, which for these data was the ECA. The best estimate rates for the individual mood and anxiety disorders were then chosen from the ECA only, in order to maintain the relationships between the individual disorders. For other disorders that were not covered in both surveys, the available estimate was used.

Key to abbreviations: ECA, Epidemiologic Catchment Area; NCS, National Comorbidity Study; GAD, generalized anxiety disorder; OCD, obsessive-compulsive disorder; PTSD, post-traumatic stress disorder; MD, major depression; ASP, antisocial personality disorder.

Source: D. Regier, W. Narrow, & D. Rae, personal communication, 1999

Table 2-7. Children and adolescents ages 9 to 17 with mental or addictive disorders,* combined MECA sample

	Prevalence (%)
Anxiety disorders	13.0
Mood disorders	6.2
Disruptive disorders	10.3
Substance use disorders	2.0
Any disorder	20.9

*Disorders include diagnosis-specific impairment and Child Global Assessment Scale ≤70 (mild global impairment).

Source: Shaffer et al., 1996

Not all mental disorders identified in childhood and adolescence persist into adulthood, even though the prevalence of mental disorders in children and adolescents is about the same as that for adults (i.e., about 20 percent of each age population). While some disorders do continue into adulthood, a substantial fraction of children and adolescents recover or "grow out of" a disorder, whereas, a substantial fraction of adults develops mental disorders in adulthood. In short, the nature and distribution of mental disorders in young people are somewhat different from those of adults.

Older Adults

The annual prevalence of mental disorders among older adults (ages 55 years and older) is also not as well documented as that for younger adults. Estimates generated from the ECA survey indicate that 19.8 percent of the older adult population have a diagnosable mental disorder during a 1-year period (Table 2-8). Almost 4 percent of older adults have SMI, and just under 1 percent has SPMI (Kessler et al., 1996); these figures do not include individuals with severe cognitive impairments such as Alzheimer's disease.

Table 2-8. Best estimate prevalence rates based on Epidemiologic Catchment Area, age 55+

	Prevalence (%)
Any Anxiety Disorder	11.4
Simple Phobia	7.3
Social Phobia	1.0
Agoraphobia	4.1
Panic Disorder	0.5
Obsessive-Compulsive Disorder	1.5
Any Mood Disorder	4.4
Major Depressive Episode	3.8
Unipolar Major Depression	3.7
Dysthymia	1.6
Bipolar I	0.2
Bipolar II	0.1
Schizophrenia	0.6
Somatization	0.3
Antisocial Personality Disorder	0.0
Anorexia Nervosa	0.0
Severe Cognitive Impairment	6.6
Any Disorder	19.8

Source: D. Regier, W. Narrow, & D. Rae, personal communication, 1999

Future Directions for Epidemiology

The epidemiology of mental disorders is somewhat handicapped by the difficulty of identifying a "case" of a mental disorder. "Case" is an epidemiological term for someone who meets the criteria for a disease or disorder. It is not always easy to establish a threshold for a mental disorder, particularly in light of how common symptoms of mental distress are and the lack of objective, physical symptoms. It is sometimes difficult to determine when a set of symptoms rises to the level of a mental disorder, a problem that affects other areas of health (e.g., criteria for certain pain syndromes). In many cases, symptoms are not of sufficient intensity or duration to meet the criteria for a disorder and the threshold may vary from culture to culture.

Diagnosis of mental disorders is made on the basis of a multidimensional assessment that takes into account observable signs and symptoms of

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illness, the course and duration of illness, response to treatment, and degree of functional impairment. One problem has been that there is no clearly measurable *threshold* for functional impairments. Efforts are currently under way in the epidemiology of mental disorders to create a threshold, or agreed-upon minimum level of functional limitation, that should be required to establish a "case" (i.e., a clinically significant condition). Epidemiology reflecting the state of psychiatric nosology during the past two decades has focused primarily on symptom clusters and has not uniformly applied—or, at times, even measured—the level of dysfunction. Ongoing reanalyses of existing epidemiological data are expected to yield better understanding of the rates of mental disorder and dysfunction in the population.

Another limitation of contemporary mental health knowledge is the lack of standard measures of "need for treatment," particularly those which are culturally appropriate. Such measures are at the heart of the public health approach to mental health. Current epidemiological estimates therefore cannot definitively identify those who are in need of treatment. Other estimates presented in Chapter 6 indicate that some individuals with mental disorders are in treatment and others are not; some are seen in primary care settings and others in specialty care. In the absence of valid measures of need, rates of disorder estimated in epidemiological surveys serve as an imperfect proxy for the need for care and treatment (Regier et al., in press).

Subsequent sections of this report reveal the population basis of our understanding of mental health. Where appropriate, the report discusses mental health and illness across the entire population. At other times, the focus is on care in specialized mental health settings, primary health care, schools, the criminal justice system, and even the streets. A mainstream public health and population-based perspective demands such a broad view of mental health and mental illness.

Costs of Mental Illness

The costs of mental illness are exceedingly high. Although the question of cost is discussed more fully in Chapter 6, a few of the central findings are presented here. The direct costs of mental health services in the United States in 1996 totaled $69.0 billion. This figure represents 7.3 percent of total health spending. An additional $17.7 billion was spent on Alzheimer's disease and $12.6 billion on substance abuse treatment. Direct costs correspond to spending for treatment and rehabilitation nationwide.

When economists calculate the costs of an illness, they also strive to identify indirect costs. Indirect costs can be defined in different ways, but here they refer to lost productivity at the workplace, school, and home due to premature death or disability. The indirect costs of mental illness were estimated in 1990 at $78.6 billion (Rice & Miller, 1996). More than 80 percent of these costs stemmed from disability rather than death because mortality from mental disorders is relatively low.

Overview of Etiology

The precise causes (etiology) of most mental disorders are not known. But the key word in this statement is *precise*. The *precise* causes of most mental disorders—or, indeed, of mental health—may not be known, but the broad forces that shape them *are* known: these are biological, psychological, and social/cultural factors.

What is most important to reiterate is that the causes of health and disease are generally viewed as a product of the *interplay* or *interaction* between biological, psychological, and sociocultural factors. This is true for all health and illness, including mental health and mental illness. For instance, diabetes and schizophrenia alike are viewed as the result of interactions between biological, psychological, and sociocultural influences. With these disorders, a biological predisposition is necessary but not sufficient to explain their occurrence (Barondes, 1993). For other disorders, a psychological or sociocultural cause may be necessary, but again not sufficient.

As described in the section on modern neuroscience, the brain and behavior are inextricably linked by the plasticity of the nervous system. The brain is the organ of mental function; psychological phenomena have their origin in that complex organ. Psychological and sociocultural phenomena are represented in the brain through memories and learning, which involve structural changes in the neurons and neuronal circuits. Yet neuroscience does not intend to reduce all phenomena to neurotransmission or to reinterpret them in a new language of synapses, receptors, and circuits. Psychological and sociocultural events and phenomena continue to have meaning for mental health and mental illness.

Much of the research that is presented in the remainder of this report draws on theories and investigations that predate the more modern view of integrative neuroscience. It is still meaningful, however, to speak of the interaction of biological and psychological and sociocultural factors in health and illness. That is where the overview of etiology begins—with the biopsychosocial model of disease, followed by an explanation of important terms used in the study of etiology. Then, against the backdrop of the introductory section on brain and behavior, the following sections address biological and psychosocial influences on mental health and mental illness, a separation that reflects the distinctive research perspectives of past decades. The overview of etiology draws to a close with a discussion of the convergence of biological and psychosocial approaches in the study of mental health and mental illness.

Biopsychosocial Model of Disease

The modern view that many factors interact to produce disease may be attributed to the seminal work of George L. Engel, who in 1977 put forward the *Biopsychosocial Model of Disease* (Engel, 1977). Engel's model is a framework, rather than a set of detailed hypotheses, for understanding health and disease. To many scientists, the model lacks sufficient specificity to make predictions about the given cause or causes of any one disorder. Scientists want to find out what *specifically* is the contribution of different factors (e.g., genes, parenting, culture, stressful events) and *how* they operate. But the purpose of the biopsychosocial model is to take a broad view, to assert that simply looking at biological factors alone—which had been the prevailing view of disease at the time Engel was writing—is not sufficient to explain health and illness.

According to Engel's model, biopsychosocial factors are involved in the causes, manifestation, course, and outcome of health and disease, including mental disorders. The model certainly fits with common experience. Few people with a condition such as heart disease or diabetes, for instance, would dispute the role of stress in aggravating their condition. Research bears this out and reveals many other relationships between stress and disease (Cohen & Herbert, 1996; Baum & Posluszny, 1999).

One single factor in isolation—biological, psychological, or social—may weigh heavily or hardly at all, depending on the behavioral trait or mental disorder. That is, the relative importance or role of any one factor in causation often varies. For example, a personality trait like extroversion is linked strongly to genetic factors, according to identical twin studies (Plomin et al., 1994). Similarly, schizophrenia is linked strongly to genetic factors, also according to twin studies (see Chapter 4). But this does not mean that genetic factors completely preordain or fix the nature of the disorder and that psychological and social factors are unimportant. These social factors modify expression and outcome of disorders. Likewise, some mental disorders, such as post-traumatic stress disorder (PTSD), are clearly caused by exposure to an extremely stressful event, such as rape, combat, natural disaster, or concentration camp (Yehuda, 1999). Yet not everyone develops PTSD after such exposure. On average, about 9 percent do (Breslau et al., 1998), but estimates are higher for particular types of trauma. For women who are victims of crime, one study found the prevalence of PTSD in a representative sample of women to be 26 percent (Resnick et al., 1993). The likelihood of developing PTSD is related to pretrauma vulnerability (in the form of genetic, biological, and personality factors), magnitude of the stressful event, preparedness for the event, and the quality of care after the event (Shalev, 1996).

The relative roles of biological, psychological, or social factors also may vary across individuals and across stages of the life span. In some people, for example, depression arises primarily as a result of exposure to stressful life events, whereas in others the foremost cause of depression is genetic predisposition.

Understanding Correlation, Causation, and Consequences

Any discussion of the etiology of mental health and mental illness needs to distinguish three key terms: correlation, causation, and consequences. These terms are often confused. All too frequently a biological change in the brain (a lesion) is purported to be the "cause" of a mental disorder, based on finding an association between the lesion and a mental disorder. The fact is that any simple association—or correlation—cannot and does not, by itself, mean causation. The lesion could be a correlate, a cause of, or an effect of the mental disorder.

When researchers begin to tease apart etiology, they usually start by noticing correlations. A correlation is an association or linkage of two (or more) events. A correlation simply means that the events are linked in some way. Finding a correlation between stressful life events and depression would prompt more research on causation. Does stress cause depression? Does depression cause stress? Or are they both caused by an unidentified factor? These would be the questions guiding research. But, with correlational research, several steps are needed before causation can be established.

If a correlational study shows that a stressful event is associated with an increased probability for depression and that the stress usually precedes depression's onset, then stress is called a "risk factor" for depression.[5] Risk factors are biological, psychological, or sociocultural variables that increase the probability for developing a disorder and antedate its onset (Garmezy, 1983; Werner & Smith, 1992; Institute of Medicine [IOM], 1994a). For each mental disorder, there are likely to be multiple risk factors, which are woven together in a complex chain of causation (IOM, 1994a). Some risk factors may carry more weight than others, and the interaction of risk factors may be additive or synergistic.

Establishing causation of mental health and mental illness is extremely difficult, as explained in Chapter 1. Studies in the form of randomized, controlled experiments provide the strongest evidence of causation. The problem is that experimental research in humans may be logistically, ethically, or financially impossible. Correlational research in humans has thus provided much of what is known about the etiology of mental disorders. Yet correlational research is not as strong as experimental research in permitting inferences about causality. The establishment of a cause and effect relationship requires multiple studies and requires judgment about the weight of *all* the evidence. Multiple correlational studies can be used to support causality, when, for example, evaluating the effectiveness of clinical treatments (Chambless et al., 1996). But, when studying etiology, correlational studies are, if possible, best combined with evidence of biological plausibility

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[5] Chapter 4 contains a fuller discussion of the relationship between stress and depression. In common parlance, stress refers either to the stressful event or to the individual's response to the event. However, mental health professionals distinguish the two by referring to the external events as the "stressor" (or stressful life event) and to the individual's response as the "stress response."

(IOM, 1994b).[6] This means that correlational findings should fit with biological, chemical, and physical findings about mechanisms of action relating to cause and effect.

Biological plausibility is often established in animal models of disease. That is why researchers seek animal models in which to study causation. In mental health research, there are some animal models—such as for anxiety and hyperactivity—but a major problem is the difficulty of finding animal models that simulate what is often uniquely human functioning. The search for animal models, however, is imperative.

Consequences are defined as the later outcomes of a disorder. For example, the most serious consequence of depression in older people is increased mortality from either suicide or medical illness (Frasure-Smith et al., 1993, 1995; Conwell, 1996; Penninx et al., 1998). The basis for this relationship is not fully known. The relationship between depression and suicide in adolescents is presented in Chapter 3.

Putting this all together, the biopsychosocial model holds that biological, psychological, or social factors may be causes, correlates, and/or consequences in relation to mental health and mental illness. A stressful life event, such as receiving the news of a diagnosis of cancer, offers a graphic example of a psychological event that causes immediate biological changes and later has psychological, biological, and social consequences. When a patient receives news of the cancer diagnosis, the brain's sensory cortex simultaneously registers the information (a correlate) and sets in motion biological changes that cause the heart to pound faster. The patient may experience an almost immediate fear of death that may later escalate to anxiety or depression. This certainly has been established for breast cancer patients (Farragher, 1998). Anxiety and depression are, in this case, *consequences* of the cancer diagnosis,[7] although the exact mechanisms are not understood. Being anxious or depressed may prompt further changes in behavior, such as social withdrawal. So there may be social consequences to the diagnosis as well. This example is designed to lay out some of the complexity of the biopsychosocial model applied to mental health and mental illness.

Biological Influences on Mental Health and Mental Illness

There are far-reaching biological and physical influences on mental health and mental illness. The major categories are genes, infections, physical trauma, nutrition, hormones, and toxins (e.g., lead). Examples have been noted throughout Chapter 1 and earlier in this chapter. This section focuses on the first two categories—genes and infections—for these are among the most exciting and intensive areas of research relating to biological influences on mental health and mental illness.

The Genetics of Behavior and Mental Illness

That genes influence behavior, normal and abnormal, has long been established (Plomin et al., 1997). Genes influence behavior across the animal spectrum, from the lowly fruitfly all the way to humans. Sorting out which genes are involved and determining how they influence behavior present the greatest challenge. Research suggests that many mental disorders arise in part from defects not in single genes, but in *multiple* genes. However, none of the genes has yet been pinpointed for common mental disorders (National Institute of Mental Health [NIMH], 1998).

The human genome contains approximately 80,000 genes that occupy approximately 5 percent of the DNA sequences of the human genome. By the spring of 2000, the human genome project will have provided an initial rough draft version of the entire sequence of the human genome, and in the ensuing years, gaps in the sequence will be closed, errors will be corrected, and the precise boundaries of genes will be identified.

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[6] Other types of information used to establish cause and effect relationships are the strength and consistency of the association, time sequence information, dose-response relationships, and disappearance of the effect when the cause is removed.

[7] Anxiety and depression may in some cases be caused by hormonal changes related to the tumor itself.

In parallel, clinical medicine is studying the aggregation of human disease in families. This effort includes the study of mental illness, most notably schizophrenia, bipolar disorder (manic depressive illness), early onset depression, autism, attention-deficit/hyperactivity disorder, anorexia nervosa, panic disorder, and a number of other mental disorders (NIMH, 1998). From studying how these disorders run in families, and from initial molecular analyses of the genomes of these families, we have learned that heredity—that is, genes—plays a role in the transmission of vulnerability of all the aforementioned disorders from generation to generation.

But we have also learned that the transmission of risk is not simple. Certain human diseases such as Huntington's disease and cystic fibrosis result from the transmission of a mutation—that is, a deleteriously altered gene sequence—at one location in the human genome. In these diseases, a single mutation has everything to say about whether one will get the illness. The transmission of a trait due to a single gene in the human genome is called Mendelian transmission, after the Austrian monk, Gregor Mendel, who was the first to develop principles of modern genetics and who studied traits due to single genes. When a single gene determines the presence or absence of a disease or other trait, genes are rather easy to discover on the basis of modern methods. Indeed, for almost all Mendelian disorders across medicine that affect more than a few people, the genes already have been identified.

In contrast to Mendelian disorders, to our knowledge, all mental illnesses and all normal variants of behavior are genetically complex. What this means is that no single gene or even a combination of genes dictates whether someone will have an illness or a particular behavioral trait. Rather, mental illness appears to result from the interaction of multiple genes that confer risk, and this risk is converted into illness by the interaction of genes with environmental factors. The implications for science are, first, that no gene is equivalent to fate for mental illness. This gives us hope that modifiable environmental risk factors can eventually be identified and become targets for prevention efforts. In addition, we recognize that genes, while significant in their aggregate contribution to risk, may each contribute only a small increment, and, therefore, will be difficult to discover. As a result, however, of the Human Genome Project, we will know the sequence of each human gene and the common variants for each gene throughout the human race. With this information, combined with modern technologies, we will in the coming years identify genes that confer risk of specific mental illnesses.

This information will be of the highest importance for several reasons. First, genes are the blueprints of cells. The products of genes, proteins, work together in pathways or in building cellular structures, so that finding variants within genes will suggest pathways that can be targets of opportunity for the development of new therapeutic interventions. Genes will also be important clues to what goes wrong in the brain when a disease occurs. For example, once we know that a certain gene is involved in risk of a particular mental illness such as schizophrenia or autism, we can ask at what time during the development of the brain that particular gene is active and in which cells and circuits the gene is expressed. This will give us clues to critical times for intervention in a disease process and information about what it is that goes wrong. Finally, genes will provide tools for those scientists who are searching for environmental risk factors. Information from genetics will tell us at what age environmental cofactors in risk must be active, and genes will help us identify homogeneous populations for studies of treatment and of prevention.

Heritability refers to how much genetics contributes to the variation of a disease or trait in a population at a given point in time (Plomin et al., 1997). Once a disorder is established as running in families, the next step is to determine its heritability (see below), then its mode of transmission, and, lastly, its location through genetic mapping (Lombroso et al., 1994).

One powerful method for estimating heritability is through twin studies.[8] Twin studies often compare the frequency with which identical versus fraternal twins display a disorder. Since identical twins are from the same fertilized egg, they share the exact genetic inheritance. Fraternal twins are from separate eggs and thereby share only 50 percent of their genetic inheritance. If a disorder is heritable, identical twins should have a higher rate of concordance—the expression of the trait by *both* members of a twin pair—than fraternal twins. Such studies, however, do not furnish information about *which* or *how many* genes are involved. They just can be used to estimate heritability. For example, the heritability of bipolar disorder, according to the most rigorous twin study, is about 59 percent, although other estimates vary (NIMH, 1998). The heritability of schizophrenia is estimated, on the basis of twin studies, at a somewhat higher level (NIMH, 1998).

Even with a high level of heritability, however, it is essential to point out that environmental factors (e.g., psychosocial environment, nutrition, health care access) can play a significant role in the severity and course of a disorder.

Another point is that environmental factors may even protect against the disorder developing in the first place. Even with the relatively high heritability of schizophrenia, the median concordance rate among identical twins is 46 percent[9] (NIMH, 1998), meaning that in over *half* of the cases, the second twin does not manifest schizophrenia even though he or she has the same genes as the affected twin. This implies that environmental factors exert a significant role in the onset of schizophrenia.

Infectious Influences

It has been known since the early part of the 20th century that infectious agents can penetrate into the brain where they can cause mental disorders. A highly common mental disorder of unknown etiology at the turn of the century, termed "general paresis," turned out to be a late manifestation of syphilis. The sexually transmitted infectious agent—*Treponema pallidum*—first caused symptoms in reproductive organs and then, sometimes years later, migrated to the brain where it led to neurosyphilis. Neurosyphilis was manifest by neurological deterioration (including psychosis), paralysis, and later death. With the wide availability of penicillin after World War II, neurosyphilis was virtually eliminated (Barondes, 1993).

Neurosyphilis may be thought of as a disease of the past (at least in the developed world), but dementia associated with infection by the human immunodeficiency virus (HIV) is certainly not. HIV-associated dementia continues to encumber HIV-infected individuals worldwide. HIV infection penetrates into the brain, producing a range of progressive cognitive and behavioral impairments. Early symptoms include impaired memory and concentration, psychomotor slowing, and apathy. Later symptoms, usually appearing years after infection, include global impairments marked by mutism, incontinence, and paraplegia (Navia et al., 1986). The prevalence of HIV-associated dementia varies, with estimates ranging from 15 percent to 44 percent of patients with HIV infection (Grant et al., 1987; McArthur et al., 1993). The high end of this estimate includes patients with subtle neuropsychological abnormalities. What is remarkable about HIV-associated dementia is that it appears to be caused not by *direct* infection of neurons, but by infection of immune cells known as macrophages that enter the brain from the blood. The macrophages *indirectly* cause dysfunction and death in nearby neurons by releasing soluble toxins (Epstein & Gendelman, 1993).

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[8] Establishing that a disorder runs in families could suggest environmental and/or genetic influences because families share genes and environment. Comparing identical versus fraternal twins assumes that their shared environments are about equal, thereby providing insight about genetic influences. Such comparisons are further enhanced by studies of twins (identical vs. fraternal) separated at birth and adopted by different families.

[9] The median concordance rate for identical twins is only 14 percent (NIMH, 1998).

Besides HIV-associated dementia and neurosyphilis, other mental disorders are caused by infectious agents. They include herpes simplex encephalitis, measles encephalomyelitis, rabies encephalitis, chronic meningitis, and subacute sclerosing panencephalitis (Kaplan & Sadock, 1998). More recently, research has uncovered an infectious etiology to one form of obsessive-compulsive disorder, as explained below.

PANDAS

In the late 1980s, it was discovered that some children with obsessive-compulsive disorder (OCD) experienced a sudden onset of symptoms soon after a streptococcal pharyngitis (Garvey et al., 1998). The symptoms were classic for OCD—concerns about contamination, spitting compulsions, and extremely excessive hoarding—but the abrupt onset was unusual. Further study of these children led to the identification of a new classification of OCD called PANDAS. This acronym stands for pediatric autoimmune neuropsychiatric disorders associated with streptococcal infection. PANDAS are distinct from classic cases of OCD because of their episodic clinical course marked by sudden symptom exacerbation linked to streptococcal infection, among other unique features. The exacerbation of symptoms is correlated with a rise in levels of antibodies that the child produces to fight the strep infection. Consequently, researchers proposed that PANDAS are caused by antibodies against the strep infection that also manage to attack the basal ganglia region of the child's brain (Garvey et al., 1998). In other words, the strep infection triggers the child's immune system to develop antibodies, which, in turn, may attack the child's brain, leading to obsessive and compulsive behaviors. Under this proposal, the strep infection does not directly induce the condition; rather, it may do so *indirectly* by triggering antibody formation. How the antibodies are so damaging to a discrete region of the child's brain and how this attack ignites OCD-like symptoms are two of the fundamental questions guiding research.

Psychosocial Influences on Mental Health and Mental Illness

This chapter thus far has highlighted some of the psychosocial influences on mental health and mental illness. Stressful life events, affect (mood and level of arousal), personality, and gender are prominent psychological influences. Social influences include parents, socioeconomic status, racial, cultural, and religious background, and interpersonal relationships. These psychosocial influences, taken individually or together, are integrated into many chapters of this report in discussions of epidemiology, etiology, risk factors, barriers to treatment, and facilitators to recovery.

Since these psychosocial influences are familiar to the general reader, detailed description of each is beyond the scope of this section (with the exception of cultural influences, which are discussed in the Overview of Cultural Diversity and Mental Health Services section). Instead, this section summarizes the sweeping theories of individual behavior and personality that inspired a vast body of psychosocial research: psychodynamic theories, behaviorism, and social learning theories. The therapeutic strategies that arose from these theories, and modifications necessary to make them relevant to the changing demography of the U.S. population, are discussed in a later section, Overview of Treatment.

Psychodynamic Theories

Psychodynamic theories of personality assert that behavior is the product of underlying conflicts over which people often have scant awareness. Sigmund Freud (1856–1939) was the towering proponent of psychoanalytic theory, the first of the 20th-century psychodynamic theories. Many of Freud's followers pioneered their own psychodynamic theories, but this section covers only psychoanalytic theory. A brief discussion of Freud's work contributes to an historical perspective of mental health theory and treatment approaches.

Freud's theory of psychoanalysis holds two major assumptions: (1) that much of mental life is unconscious (i.e., outside awareness), and (2) that past experiences, especially in early childhood, shape how a person feels and behaves throughout life (Brenner, 1978).

Freud's structural model of personality divides the personality into three parts—the id, the ego, and the superego. The id is the unconscious part that is the cauldron of raw drives, such as for sex or aggression. The ego, which has conscious and unconscious elements, is the rational and reasonable part of personality. Its role is to maintain contact with the outside world in order to help keep the individual in touch with society. As such, the ego mediates between the conflicting tendencies of the id and the superego. The latter is a person's conscience that develops early in life and is learned from parents, teachers, and others. Like the ego, the superego has conscious and unconscious elements (Brenner, 1978).

When all three parts of the personality are in dynamic equilibrium, the individual is thought to be mentally healthy. However, according to psychoanalytic theory, if the ego is unable to mediate between the id and the superego, an imbalance would occur in the form of psychological distress and symptoms of mental disorders. Psychoanalytic theory views symptoms as important only in terms of expression of underlying conflicts between the parts of personality. The theory holds that the conflicts must be understood by the individual with the aid of the psychoanalyst who would help the person unearth the secrets of the unconscious. This was the basis for psychoanalysis as a form of treatment, as explained later in this chapter.

Behaviorism and Social Learning Theory

Behaviorism (also called learning theory) posits that personality is the sum of an individual's observable responses to the outside world (Feldman, 1997). As charted by J. B. Watson and B. F. Skinner in the early part of the 20th century, behaviorism stands at loggerheads with psychodynamic theories, which strive to understand underlying conflicts. Behaviorism rejects the existence of underlying conflicts and an unconscious. Rather, it focuses on observable, overt behaviors that are learned from the environment (Kazdin, 1996, 1997). Its application to treatment of mental problems, which is discussed later, is known as behavior modification.

Learning is seen as behavior change molded by experience. Learning is accomplished largely through either classical or operant conditioning. Classical conditioning is grounded in the research of Ivan Pavlov, a Russian physiologist. It explains why some people react to formerly *neutral* stimuli in their environment, stimuli that previously would not have elicited a reaction. Pavlov's dogs, for example, learned to salivate merely at the sound of the bell, without any food in sight. Originally, the sound of the bell would not have elicited salvation. But by repeatedly pairing the sight of the food (which elicits salvation on its own) with the sound of the bell, Pavlov taught the dogs to salivate just to the sound of the bell by itself.

Operant conditioning, a process described and coined by B. F. Skinner, is a form of learning in which a voluntary response is strengthened or attenuated, depending on its association with positive or negative consequences (Feldman, 1997). The strengthening of responses occurs by positive reinforcement, such as food, pleasurable activities, and attention from others. The attenuation or discontinuation of responses occurs by negative reinforcement in the form of removal of a pleasurable stimulus. Thus, human behavior is shaped in a trial and error way through positive and negative reinforcement, without any reference to inner conflicts or perceptions. What goes on inside the individual is irrelevant, for humans are equated with "black boxes." Mental disorders represented maladaptive behaviors that were learned. They could be unlearned through behavior modification (behavior therapy) (Kazdin, 1996; 1997).

The movement beyond behaviorism was spearheaded by Albert Bandura (1969, 1977), the originator of social learning theory (also known as social cognitive theory). Social learning theory has its roots in behaviorism, but it departs in a significant way. While acknowledging classical and operant conditioning, social learning theory places far greater emphasis on a different type of learning, particularly observational learning. Observational learning occurs through selectively observing the behavior of another person, a model. When the behavior of the model is rewarded, children are more likely to imitate the behavior. For example, a child who observes another child receiving candy for a particular behavior is more likely to carry out similar behaviors. Social learning theory asserts that people's cognitions—their views, perceptions, and expectations toward their environment—affect what they learn. Rather than being passively conditioned by the environment, as behaviorism proposed, humans take a more active role in deciding what to learn as a result of cognitive processing. Social learning theory gave rise to cognitive-behavioral therapy, a mode of treatment described later in this chapter and throughout this report.

The Integrative Science of Mental Illness and Health

Progress in understanding depression and schizophrenia offers exciting examples of how findings from different disciplines of the mental health field have many common threads (Andreasen, 1997). Despite the differences in terminology and methodology, the results from different disciplines have converged to paint a vivid picture of the nature of the fundamental defects and the regions of the brain that underlie these defects. Even in the case of depression and schizophrenia, there is much to be uncovered about etiology, yet the mental health field is seen as poised "to use the power of multiple disciplines." The disciplines are urged to link together the study of the mind and the brain in the search for understanding mental health and mental illness (Andreasen, 1997).

This linkage already has been cemented between cognitive psychology, behavioral neurology, computer science, and neuroscience. These disciplines have knit together the field of "cognitive neuroscience" (Kosslyn & Shin, 1992). This new and joint discipline has carved out its own professional society, journals (Waldrop, 1993), and textbooks (Gazzaniga et al., 1998). There is movement toward integration of other disciplines within the field. To promote linkages between psychiatry and the neurosciences, neuroscientist Eric R. Kandel has furnished a novel approach. His essay, "A New Intellectual Framework for Psychiatry," supplies a set of biological principles to forge a rapprochement—conceptual as well as practical—between the two disciplines (Kandel, 1998). Integrated approaches are seen as vital to tackle the monumental complexity of mental function.

Overview of Development, Temperament, and Risk Factors

How we come to be the way we are is through the process of development. Generally defined as the lifelong process of growth, maturation, and change, development is the product of the elaborate interplay of biological, psychological, and social influences. By studying development, researchers hope to uncover the origins of both mental health and mental illness.

This section elaborates and extends concepts introduced above regarding the fundamental workings of the brain at different developmental stages. It then proceeds to explain several seminal theories of development pioneered by Jean Piaget, Erik Erikson, and John Bowlby. Their theories cover cognitive development, personality development, and social development, respectively.

although there is some overlap. Their major works, published in the 1950s and 1960s, were pivotal for the psychological and social sciences, galvanizing a huge body of theoretical and empirical research. However, with the advancements of science and the diversity of the population, these models may not apply to all groups without some adaptation for cultural context. The section concludes with a reminder that the brain is the "great synthesizer" of the many biological, psychological, and sociocultural phenomena that make us who we are.

Physical Development

Physical development of the nervous system provides the architecture for mental function (cognition, mood, and intentional behavior). As can be inferred from the discussion of brain complexity in the introductory section, nervous system development is arguably one of the most monumentally complicated developmental achievements. One hundred billion neurons must form elaborate and precise arrays of interconnections. Neurons begin the developmental process as undifferentiated cells, cells so seemingly anonymous that they are almost indistinguishable from other cells in an embryo. On the basis of genetic and epigenetic[10] influences, the cells must first specialize, or differentiate, into neurons, migrate to their final position, and then send their growing axons (the branch of a neuron that transmits impulses) to project over long distances in order to form synapses with distant target cells (Kandel et al., 1995).

Most neurobiologists are astounded at the level of precision that neurons achieve in their interconnections. The process of nervous system development has been studied at increasingly complex levels—molecular, cellular, tissue, and behavioral levels. Yet, while researchers have charted many of the behavioral milestones of development because they are so amenable to observation and analysis, far less is known about molecular, cellular, and tissue interactions that underlie them.

Four overarching findings or organizing principles have been gleaned from decades of neuroscience research. The first finding is that the formation of connections between neurons and their target cells depends on axons growing along anatomical pathways that are studded with signaling molecules, much like landing lights illuminate the runway for a descending plane. The second finding is that an axon's reaching the vicinity of, and locating, its correct target cell depends on diffusable chemical signals being transmitted from the target cell. The third finding is that if an axon does not reach its correct target, it is likely to die. This phenomenon, known as cell death, or apoptosis, is so common that it affects up to half of all developing neurons. The brain overproduces the number of cells it needs, from which it pares down to only the correct connections (Kandel et al., 1995). Finally, neuron *activity* is essential to strengthening the connections that are formed. In other words, stimulation from the environment—which is translated into neuron activity—is vital for the forging of normal neural development (Shatz, 1993; Kandel, 1995). This is a fundamental principle that is revisited later in this section. This principle helps to explain why, for example, babies who are deprived of a stimulating environment during their first year sometimes suffer irreparable developmental effects.

Behavior at birth consists of a repertoire of simple reflexes, that is, inborn neurological reactions that are involuntary in nature. Two examples are the sucking reflex and the rooting reflex,[11] both of which are designed to ensure food intake. Over time, the infant displays an expanded repertoire of fine and gross motor skills (e.g., crawling, walking) that begin to unfold in the first few months and year of life. These include the cherished ability to smile, which helps to solidify a social bond with parents and caregivers. What begins as a child's biological survival need for food—evidenced by such behaviors as rooting and sucking—can turn into a social, interpersonal experience with the caregiver, as in the smile of an infant at the sight of a nurturing parent. These burgeoning motor capabilities are the forerunners of more complex behavioral and mental functions, but the actual relationships between early and later abilities, and their molecular and cellular basis, are understood only in the most rudimentary terms.

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[10] Epigenetic influences are those that arise from outside the genes and lead to emergent, as opposed to predetermined, properties.

[11] Newborns turn their head towards things—typically the breast—that touch their cheek.

Theories of Psychological Development

Theories of human development are grounded in the developmental perspective. The developmental perspective takes into account the biological, social, and psychological environment; their interaction; and their combined effect upon the individual throughout the life span. Developmentalist L. Breger (1974) proposes that the developmental perspective incorporates three key precepts:

- Behavioral maturation proceeds from the simple to the complex;
- Future behaviors, whether temporally near or distant, are a product of their antecedents (prior responses to the developmental environment); and
- The human response to a particular event or experience often depends on the developmental stage at which the experience occurs.

Each of these precepts is thought to apply to neurobiological development, as well as behavioral/psychosocial development. Moreover, each has implications for whether an individual experiences either healthful or unhealthful development that may lead to a mental disorder.

The three precepts are at the heart of each of the three major mainstream theories of developmental psychology that have guided research and increased our understanding of both normal and abnormal human development across the life span. The following paragraphs offer brief sketches of the developmental theories of Jean Piaget, Erik Erikson, and John Bowlby; again, these sketches are provided to afford the reader an historical perspective of research on psychological development.

Piaget: Cognitive Developmental Theory

Jean Piaget formulated one of the most influential theories of cognitive development (Inhelder & Piaget, 1958). Its focus was on cognitive (intellectual) development, that is, the processes by which children come to know and understand the world. Other aspects of human growth, both physical and emotional, are beyond the scope of his theory. Piaget posited that each step of cognitive development proceeds from the previous step in a fixed pattern, beginning at birth and ending in the teen years.

Piaget had a seminal influence on the discipline of cognitive psychology. Although empirical research has called into question some of the specifics of his theories, the broad outlines remain widely accepted.

Erik Erikson: Psychoanalytic Developmental Theory

The psychoanalytic theory of development is best exemplified in the work of Erik Erikson, a psychoanalyst who expanded upon Freud's original theories of psychosexual development. One of Erikson's pioneering contributions was that development unfolded throughout the life span, a view that has become widely embraced.

Freud postulated that development proceeded through a series of stages in which children seek pleasure or gratification from a particular body part (i.e., the oral, anal, and phallic stage). In contrast, Erikson's theories of child development focus on the interrelationship between a developing child's internal psychosexual development and his or her more external emotional development, emphasizing the interpersonal relationships that arise between the child and parents (Erikson, 1950).

Erikson conceived of the life course, from birth to old age, as a series of eight epigenetic stages that, as other developmental theories, proceed in a stepwise fashion, the next dependent upon how well the previous has been mastered: trust versus mistrust; autonomy versus shame and doubt; initiative versus guilt; industry versus inferiority; identity versus role diffusion; intimacy versus isolation; generativity versus stagnation; ego integrity versus despair.

Erikson portrayed each stage as a crisis or conflict that needed resolution, either at the time or at a subsequent stage. Each successive stage presents its own challenges but, at the same time, offers the opportunity for correction of unresolved challenges of previous stages. At each stage the tension was between the psychosocial and psychosexual—the outward-looking versus inward-looking perspectives. Psychopathology, in the form of a mental disorder, would arise if a stage was ultimately not mastered successfully.

Over the years, Erikson's theory has had great heuristic value to guide theorists and practitioners in organizing their approach to mental health and mental illness. However, his theory does not readily lend itself to empirical scrutiny. His theory also has been criticized as reflecting the concerns of male European culture (where Erikson was born and trained before moving to the United States) rather than those of women and other cultures. The need for cultural sensitivity and competence is discussed later in this chapter.

John Bowlby: Attachment Theory of Development

Fifty years ago, a new conceptualization of the psychoanalytic approach to development came into the lexicon of human development theory. John Bowlby's reinterpretation of Freudian development is grounded in both Darwinian evolutionary theory and animal ethology. The previous work of Konrad Lorenz and others, who explored the relationship between other animals and their caregivers, determined that the bonds of infant care and the attachment of young to their caregivers are seminal in the drive for survival. Similarly, Bowlby theorized that for humans, attachment to a caregiver had a biological basis in the need for survival (Bowlby, 1951). Moreover, he suggested that this attachment drive exists alongside the drive for nutrition and the sex drive, yet distinct and separate from them. Attachment is seen as the anchor that enables the developing child to explore the world.

With the comfort and security of a stable and routine attachment to the mother—or other primary caregiver—a child is able to organize other elements of development in a coherent way. In contrast, instability in the caregiving relationship—whether physical distance, erratic patterns of parental behavior, or even physical or emotional abuse—may interfere with the sense of trust and security, potentially giving rise to anxiety and psychological problems later in childhood or even decades later in life.

Nature and Nurture: The Ultimate Synthesis

For over a century, an intense debate among developmentalists and other scientists has pitted nature (genetic inheritance) against nurture (environment) as the engine of human development and behavior. Francis Galton, a 19th-century geneticist and cousin of Charles Darwin, declared that "there is no escape from the conclusion that nature prevails enormously over nurture" (cited in Plomin, 1996). As the debate raged, either nature or nurture gained ascendancy. During the 1940s and 1950s, for example, behaviorism held sway over American psychology with its argument that nurture was preeminent.

The pendulum now is coming to rest with the recognition that behavior is the product of both nature and nurture (Plomin, 1996). Each contributes to the development of mental health and mental illness. Nature and nurture are not necessarily independent forces but can interact with one another: nature can influence nurture, and nurture can influence nature (Plomin, 1996).

Studies comparing identical and fraternal twins have shed light on the contributions of nature and nurture. These studies show that for many behavioral traits, as well as mental disorders, there is a noticeable heritable component (see earlier discussion of heritability). Yet even with the most highly heritable traits or conditions, identical twins who share the same genetic endowment display marked differences. Identical twins, for example, are concordant for schizophrenia in 46 percent of pairs (NIMH, 1998), meaning that more than 50 percent of pairs are *not* concordant. Something yet unknown about the environment protects against the development of schizophrenia in genetically identical individuals (Plomin, 1996).

How do nature and nurture interact? This question cannot be directly answered by twin studies. Animal models have proven to be fertile ground for study of the mechanisms—at the molecular and cellular level—by which nature and nurture interact. As reviewed earlier, research in different animal models has established that the environment can alter the *structure* and *function* of the central nervous system (Baily & Kandel, 1993). This holds true not only during early development, but also into adulthood. Nurture influences nature, right down to detectable changes in the brain.

During development of the nervous system, each neuron forms myriad intricate synaptic connections with other neurons, the outcome of the interaction of genes and the environment described above. In this case, the environment is a very general term—it denotes the local extracellular environment surrounding the growing neuron, as well as what we traditionally think of as the environment (sensory environment, psychosocial environment, diet, etc.). When a neuron forms a synapse with its target cell, the pattern of activity, usually furnished by external environmental stimulation, strengthens or weakens the developing synapse. Only strengthened synaptic connections survive early development to form enduring connections, while weakened synaptic connections are eliminated (Shatz, 1993; Kandel et al., 1995). For example, kittens deprived of visual experience early in life sustain permanent disruption to synapses in parts of their visual cortex (Hubel & Wiesel, 1970).

Later in the course of development, established patterns of connections still can be altered by the environment—through learning. Studies in a variety of animal models have found that certain forms of learning lead to changes in the structure and function of neurons. With long-term memory—the long-term storage of learned information—these changes take the form of an enhanced number of synaptic connections and increased gene expression (Kandel et al., 1995). Increased gene expression appears to be for synthesis of new proteins needed for the structural changes occurring at the synapse (Bailey & Kandel, 1993).

Researchers continue to probe for changes in the brain associated with mental disorders. They have found, for instance, that repeated stress from the environment affects the hippocampus, an area of the brain located deep within the cerebral hemispheres. Research in animals has shown that repeated stress triggers atrophy of dendrites of certain types of neurons in a segment of the hippocampus (Sapolsky, 1996; McEwen, 1998). Similarly, imaging studies in humans suggest that stress-related disorders (e.g., post-traumatic stress disorder) induce possibly irreversible atrophy of the hippocampus (McEwen & Magarinos, 1997). Anxiety disorders also alter neuroendocrine systems (Sullivan et al., 1998). These are some of the tantalizing ways in which nurture influences nature.

The mental health field is far from a complete understanding of the biological, psychological, and sociocultural bases of development, but development clearly involves interplay among these influences. Understanding the process of development requires knowledge, ranging from the most fundamental level—that of gene expression and interactions between molecules and cells—all the way up to the highest levels of cognition, memory, emotion, and language. The challenge requires integration of concepts from many different disciplines. A fuller understanding of development is not only important in its own right, but it is expected to pave the way for our ultimate understanding of mental health and mental illness and how different factors shape their expression at different stages of the life span.

Overview of Prevention

The field of public health has long recognized the imperative of prevention to contain a major health problem (IOM, 1988). The principles of prevention were first applied to infectious diseases in the form of mass vaccination, water safety, and other forms of public hygiene. As successes amassed, prevention came to be applied to other areas of health, including chronic diseases (IOM, 1994a). A landmark report published by the Institute of Medicine in 1994 extended the concept of prevention to mental disorders (IOM, 1994a). *Reducing Risks for Mental Disorders* evaluated the body of research on the prevention of mental disorders, offered new definitions of prevention, and provided recommendations on Federal policies and programs, among other goals.

Preventing an illness from occurring is inherently better than having to treat the illness after its onset. In many areas of health, increased understanding of etiology and the role of risk and protective factors in the onset of health problems has propelled prevention. In the mental health field, however, progress has been slow because of two fundamental and interrelated problems: for most major mental disorders, there is insufficient understanding about etiology and/or there is an inability to alter the *known* etiology of a particular disorder. While these have stymied the development of prevention interventions, some successful strategies have emerged in the absence of a full understanding of etiology.

Rigorous scientific trials have documented successful prevention programs in such areas as dysthymia and major depressive disorder (Munoz et al., 1987; Clarke et al., 1995), conduct problems (Berrento-Clement et al., 1984), and risky behaviors leading to HIV infection (Kalichman et al., in press) and low birthweight babies (Olds et al., 1986). Much progress also has been made to prevent the occurrence of lead poisoning, which, if unchecked, can lead to serious and persistent cognitive deficits in children (Centers for Disease Control and Prevention, 1991; Pirkle et al., 1994). Lastly, historical milestones in prevention of mental illness led to the successful eradication of neurosyphilis, pellagra, and measles encephalomyelitis (measles invasion of the brain) in the developed world.

Definitions of Prevention

The term "prevention" has different meanings to different people. It also has different meanings to different fields of health. The classic definitions used in public health distinguish between primary prevention, secondary prevention, and tertiary prevention (Commission on Chronic Illness, 1957). Primary prevention is the prevention of a disease before it occurs; secondary prevention is the prevention of recurrences or exacerbations of a disease that already has been diagnosed; and tertiary prevention is the reduction in the amount of disability caused by a disease to achieve the highest level of function.

The Institute of Medicine report on prevention identified problems in applying these definitions to the mental health field (IOM, 1994a). The problems stemmed mostly from the difficulty of diagnosing mental disorders and from shifts in the definitions of mental disorders over time (see Diagnosis of Mental Illness). Consequently, the Institute of Medicine redefined prevention for the mental health field in terms of three core activities: prevention, treatment, and maintenance (IOM, 1994a). Prevention, according to the IOM report, is similar to the classic concept of primary prevention from public health; it refers to interventions to ward off the initial onset of a mental disorder. Treatment refers to the identification of individuals with mental disorders and the standard treatment for those disorders, which includes interventions to reduce the likelihood of future co-occurring disorders. And maintenance refers to interventions that are oriented to reduce relapse and recurrence and to provide rehabilitation. (Maintenance incorporates what the public health field traditionally defines as some forms of secondary and all forms of tertiary prevention.)

The Institute of Medicine's new definitions of prevention have been very important in conceptualizing the nature of prevention activities for mental disorders; however, the terms have not yet been universally adopted by mental health researchers. As a result, this report strives to use the terms employed by the researchers themselves. To avoid confusion, the report furnishes the relevant definition along with study descriptions.

When the term "prevention" is used in this report *without a qualifying term*, it refers to the prevention of the initial onset of a mental disorder or emotional or behavioral problem, including prevention of comorbidity. First onset corresponds to the initial point in time when an individual's mental health problems meet the full criteria for a diagnosis of a mental disorder.

Risk Factors and Protective Factors

The concepts of risk and protective factors, risk reduction, and enhancement of protective factors (also sometimes referred to as fostering resilience) are central to most empirically based prevention programs. Risk factors are those characteristics, variables, or hazards that, if present for a given individual, make it more likely that this individual, rather than someone selected at random from the general population, will develop a disorder (Garmezy, 1983; Werner & Smith, 1992; IOM, 1994a). To qualify as a risk factor the variable must antedate the onset of the disorder. Yet risk factors are not static. They can change in relation to a developmental phase or a new stressor in one's life, and they can reside within the individual, family, community, or institutions. Some risks such as gender and family history are fixed; that is, they are not malleable to change. Other risk factors such as lack of social support, inability to read, and exposure to bullying can be altered by strategic and potent interventions (Coie & Krehbiel, 1984; Silverman, 1988; Olweus, 1991; Kellam & Rebok, 1992). Current research is focusing on the interplay between biological risk factors and psychosocial risk factors and how they can be modified. As explained earlier, even with a highly heritable condition such as schizophrenia, concordance studies show that in over half of identical twins, the second twin does not have schizophrenia. This suggests the possibility of modifying the environment to eventually prevent the biological risk factor (i.e., the unidentified genes that contribute to schizophrenia) from being expressed.

Prevention not only focuses on the risks associated with a particular illness or problem but also on protective factors. Protective factors improve a person's response to some environmental hazard resulting in an adaptive outcome (Rutter, 1979). Such factors, which can reside with the individual or within the family or community, do not necessarily foster normal development in the absence of risk factors, but they may make an appreciable difference on the influence exerted by risk factors (IOM, 1994a). There is much to be learned in the mental health field about the role of protective factors across the life span and within families as well as individuals. The potential for altering these factors in intervention studies is enormous. The construct of "resilience" is related to the concept of protective factors, but it focuses more on the ability of a single individual to withstand chronic stress or recover from traumatic life events. There are many different perceptions of what constitutes resilience or "competence," another related term. Despite the increasing popularity of these ideas, "virtually no intervention studies have been conducted that test the outcomes of resilience variables" (Grover, 1998).

Preventive researchers use risk status to identify populations for intervention, and then they target risk factors that are thought to be causal and malleable and target protective factors that are to be enhanced. If the interventions are successful, the amount of risk decreases, protective factors increase, and the likelihood of onset of the potential problem also decreases. The risks for onset of a disorder are likely to be somewhat different from the risks involved in relapse of a previously diagnosed condition. This is an important distinction because at-risk terminology is used throughout the mental health intervention spectrum. The optimal treatment protocol for an individual with a serious mental condition aims to reduce the length of time the disorder exists, halt a progression of severity, and halt the recurrence of the original disorder, or if not possible, to increase the length of time between episodes (IOM, 1994a). To do this requires an assessment of the individual's specific risks for recurrence.

Many mental health problems, especially in childhood, share some of the same risk factors for initial onset, so targeting those factors can result in positive outcomes in multiple areas. Risk factors that are common to many disorders include individual factors such as neurophysiological deficits, difficult temperament, chronic physical illness, and below-average intelligence; family factors such as severe marital discord, social disadvantage, overcrowding or large family size, paternal criminality, maternal mental disorder, and admission into foster care; and community factors such as living in an area with a high rate of disorganization and inadequate schools (IOM, 1994a). Also, some individual risk factors can lead to a state of vulnerability in which other risk factors may have more effect. For example, low birthweight is a general risk factor for multiple physical and mental outcomes; however, when it is combined with a high-risk social environment, it more consistently has poorer outcomes (McGauhey et al., 1991). The accumulation of risk factors usually increases the likelihood of onset of disorder, but the presence of protective factors can attenuate this to varying degrees.

The concept of accumulation of risks in pathways that accentuate other risks has led prevention researchers to the concept of "breaking the chain at its weakest links" (Robins, 1970; IOM, 1994a). In other words, some of the risks, even though they contribute significantly to onset, may be less malleable than others to intervention. The preventive strategy is to change the risks that are most easily and quickly amenable to intervention. For example, it may be easier to prevent a child from being disruptive and isolated from peers by altering his or her classroom environment and increasing academic achievement than it is to change the home environment where there is severe marital discord and substance abuse.

Because mental health is so intrinsically related to all other aspects of health, it is imperative when providing preventive interventions to consider the interactions of risk and protective factors, etiological links across domains, and multiple outcomes. For example, chronic illness, unemployment, substance abuse, and being the victim of violence can be risk factors or mediating variables for the onset of mental health problems (Kaplan et al., 1987). Yet some of the same factors also can be related to the consequences of mental health problems (e.g., depression may lead to substance abuse, which in turn may lead to lung or liver cancer).

Overview of Treatment

Introduction to Range of Treatments

Mental disorders are treatable, contrary to what many think.[12] An armamentarium of efficacious treatments is available to ameliorate symptoms. In fact, for most mental disorders, there is generally not just one but a *range* of treatments of proven efficacy. Most treatments fall under two general categories, psychosocial and pharmacological.[11] Moreover, the combination of the two—known as multimodal therapy—can sometimes be even more effective than each individually (see Chapter 3).

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[12] About 40 percent of those surveyed thought that they "didn't think anyone could help" as a reason for not seeking mental health treatment (Sussman et al., 1987).

The evidence for treatment being more effective than placebo is overwhelming, as documented in the main chapters of this report (Chapters 3 through 5). The degree of effectiveness tends to vary, depending on the disorder and the target population (e.g., older adults with depression). What is optimal for one disorder and/or age group may not be optimal for another. Further, treatments generally need to be tailored to the client and to client preferences.

The inescapable point is that studies demonstrate conclusively that treatment is more effective than placebo. Placebo (an inactive form of treatment) in both pharmacological and psychotherapy studies has a powerful effect in its own right, as this section later explains. Placebo is more effective than no treatment. Therefore, to capitalize on the placebo response, people are encouraged to seek treatment, even if the treatment is not as optimal as that described in this report.

If treatment is so effective, then why are so few people receiving it? Studies reveal that less than one-third of adults with a diagnosable mental disorder, and even a smaller proportion of children, receive any mental health services in a given year. This section of the chapter strives to explain why by examining the types of barriers that prevent people from seeking help. But the chapter first covers some general points about psychological and pharmacological therapies. It also discusses why therapies that work so well in research settings do not work as well in practice.

Psychotherapy

Psychotherapy is a learning process in which mental health professionals seek to help individuals who have mental disorders and mental health problems. It is a process that is accomplished largely by the exchange of verbal communication, hence it often is referred to as "talk therapy." Many of the theories undergirding each orientation to psychotherapy were summarized earlier in this chapter.

Participants in psychotherapy can vary in age from the very young to the very old, and problems can vary from mental health problems to disabling and catastrophic mental disorders. Although people often are seen individually, psychotherapy also can be done with couples, families, and groups. In each case, participants present their problems and then work with the psychotherapist to develop a more effective means of understanding and handling their problems. This report focuses on individual psychotherapy and also mentions couples therapy and various forms of family interventions, particularly psycho-educational approaches. Although not discussed in the report, group psychotherapy is effective for selected individuals with some mood disorders, anxiety disorders, schizophrenia, personality disorders, and for mental health problems seen in somatic illness (Yalom, 1995; Kanas, in press).

Estimates of the number of orientations to psychotherapy vary from a very small number to well over 400. The larger estimate generally refers to all the variations of the three major orientations, that is, psychodynamic, behavioral, and humanistic. Each orientation falls under the more general conceptual category of either action or reflection.

Psychodynamic orientations are the oldest. They place a premium on self-understanding, with the implicit (or sometimes explicit) assumption that increased self-understanding will produce salutary changes in the participant. Behavioral orientations are geared toward action, with a clear attempt to mobilize the resources of the patient in the direction of change, whether or not there is any understanding of the etiology of the problem. Humanistic orientations aim toward increased self-understanding, often in the direction of personal growth, but use treatment techniques that often are much more active than are likely to be employed by the psychodynamic clinician.

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[11] Other treatments are electroconvulsive therapy (Chapters 4 and 5) and some types of surgery.

While the following paragraphs focus on psychodynamic, behavioral, and humanistic orientations, they also discuss interpersonal therapy and cognitive-behavioral therapy as outgrowths of psychodynamic and behavioral therapy, respectively. Psychodynamic, interpersonal, and cognitive-behavioral therapy are most commonly the focus of treatment research reported throughout this report.

Psychodynamic Therapy

The first major approach to psychotherapy was developed by Sigmund Freud and is called psychoanalysis (Horowitz, 1988). Since its origin more than a century ago, psychoanalysis has undergone many changes. Today, Freudian (or classical) psychoanalysis is still practiced, but other variations have been developed—ego psychology, object relations theory, interpersonal psychology, and self-psychology, each of which can be grouped under the general term "psychodynamic" (Horowitz, 1988). The psychodynamic therapies, even though they differ somewhat in theory and approach, all have some concepts in common. With each, the role of the past in shaping the present is emphasized, so it is important, in understanding behavior, to understand its origins and how people come to act and feel as they do. A second critical concept common to all psychodynamic approaches is the belief in the unconscious, so that there is much that influences our behavior of which we are not aware. This makes the process of understanding more difficult, as we often act for reasons that we cannot state, and these reasons often are linked to previous experiences. Thus, an important part of psychodynamic psychotherapy is to make the unconscious conscious or to help the patient understand the origin of actions that are troubling so that they can be corrected.

For some psychodynamic approaches, such as the classical Freudian approach, the focus is on the individual and the experiences the person had in the early years that give shape to current behavior, even beyond the awareness of the patient. For other, more contemporary approaches, such as *interpersonal therapy*, the focus is on the relationship between the person and others. First developed as a time-limited treatment for midlife depression, interpersonal therapy focuses on grief, role disputes, role transitions, and interpersonal deficits (Klerman et al., 1984). The goal of interpersonal therapy is to improve current interpersonal skills. The therapist takes an active role in teaching patients to evaluate their interactions with others and to become aware of self-isolation and interpersonal difficulties. The therapist also offers advice and helps the patient to make decisions.

Behavior Therapy

A second major approach to psychotherapy is known as behavior modification or behavior therapy (Kazdin, 1996, 1997). It focuses on current behavior rather than on early patterns of the patient. In its earlier form, behavior therapy dealt exclusively with what people did rather than what they thought or felt. The general principles of learning were applied to the learning of maladaptive as well as adaptive behaviors. Thus, if a person could be conditioned to act in a functional way, there was no reason why the same principles of conditioning could not be employed to help the person unlearn dysfunctional behavior and learn to replace it with more functional behavior. The role of the environment was very important for behavior therapists, because it provided the positive and negative reinforcements that sustained or eliminated various behaviors. Therefore, ways of shaping that environment to make it more responsive to the needs of the individual were important in behavior therapy.

More recently, there has been a significant addition to the interests and activities of behavior therapists. Although behavior continued to be important in relation to reinforcements, cognitions—what the person *thought* about, perceived, or interpreted what was transpiring—were also seen as important. This combined emphasis led to a therapeutic variant known as *cognitive-behavioral therapy*, an approach that incorporates cognition with behavior in understanding and altering the problems that patients present (Kazdin, 1996).

Cognitive-behavioral therapy draws on behaviorism as well as cognitive psychology, a field devoted to the scientific study of mental processes, such as perceiving, remembering, reasoning, decisionmaking, and problem solving. The use of cognition in cognitive-behavioral therapy varies from attending to the role of the environment in providing a model for behavior, to the close study of irrational beliefs, to the importance of individual thought processes in constructing a vision of the surrounding world. In each case, it is critical to study what the individual in therapy thinks and does and less important to understand the past events that led to that pattern of thinking and doing. Cognitive-behavioral therapy strives to alter faulty cognitions and replace them with thoughts and self-statements that promote adaptive behavior (Beck et al., 1979). For instance, cognitive-behavioral therapy tries to replace self-defeatist expectations ("I can't do anything right") with positive expectations ("I can do this right"). Cognitive-behavioral therapy has gained such ascendancy as a means of integrating cognitive and behavioral views of human functioning that the field is more frequently referred to as cognitive-behavioral therapy rather than behavior therapy (Kazdin, 1996).

Humanistic Therapy

The third wave of psychotherapy is referred to variously as humanistic (Rogers, 1961), existential (Yalom, 1980), experiential, or Gestalt therapy. It owes its origins as a treatment to the client-centered therapy that was originated by Carl Rogers, and the theory can be traced to philosophical roots beginning with the 19th century philosopher, Soren Kierkegaard. The central focus of humanistic therapy is the immediate experience of the client. The emphasis is on the present and the potential for future development rather than on the past, and on immediate feelings rather than on thoughts or behaviors. It is rooted in the everyday subjective experience of the person seeking assistance and is much less concerned with mental illness than it is with human growth.

One critical aspect of humanistic treatment is the relationship that is forged between the therapist, who in some ways serves as a guide in an exploration of self-discovery, and the client, who is seeking greater knowledge of the self and an expansion of inherent human potential. The focus on the self and the search for self-awareness is akin to psychodynamic psychotherapy, while the emphasis on the present is more similar to behavior therapy.

Although it is possible to describe distinctive orientations to psychotherapy, as has been done above, most psychotherapists describe themselves as eclectic in their practice, rather than as adherents to any single approach to treatment. As a result, there is a growing development referred to as "psychotherapy integration" (Wolfe & Goldfried, 1988). It strives to capture what is best about each of the individual approaches. Psychotherapy integration includes various attempts to look beyond the confines of any single orientation but rather to see what can be learned from other perspectives. It is characterized by an openness to various ways of integrating diverse theories and techniques. Psychotherapy also should be modified to be culturally sensitive to the needs of racial and ethnic minorities (Acosta et al., 1982; Sue et al., 1994; Lopez, in press).

The scientific evidence on efficacy presented in this report, however, is focused primarily on specific, standardized forms of psychotherapy.

Pharmacological Therapies

The past decade has seen an outpouring of new drugs introduced for the treatment of mental disorders (Nemeroff, 1998). New medications for the treatment of depression and schizophrenia are among the achievements stoked by research advances in both neuroscience and molecular biology. Through the process known as rational drug design, researchers have become increasingly sophisticated at designing drugs by manipulating their chemical structures. Their goal is to create more effective therapeutic agents, with fewer side effects, exquisitely targeted to correct the biochemical alterations that accompany mental disorders.

The process was not always so rational. Many of the older pharmacotherapies (drug treatments) that had been introduced by 1960 had been discovered largely by accident. Researchers studying drugs for completely different purposes serendipitously found them to be useful for treating mental disorders (Barondes, 1993). Thanks to their willingness to follow up on unexpected leads, drugs such as chlorpromazine (for psychosis), lithium (for bipolar disorder), and imipramine (for depression) became available. The advent of chlorpromazine in 1952 and other neuroleptic drugs was so revolutionary that it was one of the major historical forces behind the deinstitutionalization movement that is discussed later in this chapter.

The past generation of pharmacotherapies, once shown to be safe and effective, was introduced to the market generally before their mechanism of action was understood. Years of research after their introduction revealed how many of them work therapeutically. Knowledge about their actions has had two cardinal consequences: it helped probe the etiology of mental disorders, and it ushered in the next generation of pharmacotherapies that are more selective in their mechanism of action.

Mechanisms of Action

The mechanism of action refers to how a pharmacotherapy interacts with its target in the body to produce therapeutic effects. Pharmacotherapies that act in similar ways are grouped together into broad categories (e.g., stimulants, antidepressants). Within each category are several chemical classes. The individual pharmacotherapies within a chemical class share similar chemical structures. Table 2-9 presents several common categories and classes, along with their indication, that is, their clinical use.

Many pharmacotherapies for mental disorders have as their initial action the alteration—either increase or decrease—in the amount of a neurotransmitter. Neurotransmitter levels can be altered by pharmacotherapies in myriad ways: pharmacotherapies can mimic the action of the neurotransmitter in cell-to-cell signaling; they can block the action of the neurotransmitter; or they can alter its synthesis, breakdown (degradation), release, or reuptake, among other possibilities (Cooper et al., 1996).

Neurotransmitters generally are concentrated in separate brain regions and circuits. Within the cells that form a circuit, each neurotransmitter has its own biochemical pathway for synthesis, degradation, and reuptake, as well as its own specialized molecules known as receptors. At the time of neurotransmission, when a traveling signal reaches the tip (terminal) of the presynaptic cell, the neurotransmitter is released from the cell into the synaptic cleft. It migrates across the synaptic cleft in less than a millisecond and then binds to receptors situated on the membrane of the postsynaptic cell. The neurotransmitter's binding to the receptor alters the shape of the receptor in such a way that the neurotransmitter can either excite the postsynaptic cell, and thereby transmit the signal to this next cell, or inhibit the receptor, and thereby block signal transmission. The neurotransmitter's action is terminated either by enzymes that degrade it right there, in the synaptic cleft, or by transporter proteins that return unused neurotransmitter back to the presynaptic neuron for reuse, a "recycling" process known as reuptake. The widely prescribed class of antidepressants referred to as the selective

Table 2-9. Selected types of pharmacotherapies

Category and Class	Example(s) of Clinical Use
Antipsychotics (neuroleptics)	Schizophrenia, psychosis
Typical antipsychotics*	
Atypical antipsychotics**	
Antidepressants	Depression, anxiety
Selective serotonin reuptake inhibitors	
Tricyclic and heterocyclic antidepressants***	
Monoamine oxidase inhibitors	
Stimulants	Attention-deficit/hyperactivity disorder
Antimanic	Mania
Lithium	
Anticonvulsants	
Thyroid supplementation	
Antianxiety (anxiolytics)	Anxiety
Benzodiazepines	
Antidepressants	
β-Adrenergic-blocking drugs	
Cholinesterase inhibitors	Alzheimer's disease

* Also known as first-generation antipsychotics, they include these chemical classes: phenothiazines (e.g., chlorpromazine), butyrophenones (e.g., haloperidol), and thioxanthenes (Dixon et al., 1995).

** Also known as second-generation antipsychotics, they include these chemical classes: dibenzoxazepine (e.g., clozapine), thienobenzodiazepine (e.g., olanzapine), and benzisoxazole (e.g., risperidone).

*** Include imipramine and amitriptyline.

Source: Perry et al., 1997

serotonin reuptake inhibitors primarily block the action of the transporter protein for serotonin, thus leaving more serotonin to remain at the synapse (Schloss & Williams, 1998). Depression is thought to be reflected in decreased serotonin transmission, so one rationale for this class of antidepressants is to boost the level of serotonin (see Chapter 4).

Although the effects of reuptake inhibitors on neurotransmitter concentrations in the synapse occur with the first dose, therapeutic benefit typically lags behind by days or weeks. This observation has spurred considerable recent research on chronic and "downstream" actions of psychotropics, particularly antidepressants. For example, in animal models the repeated administration of nearly all antidepressants is associated with a reduction in the number of postsynaptic β receptors, so-called down-regulation that parallels the time course of clinical effect in patients (Schatzberg & Nemeroff, 1998). Some of the secondary effects of reuptake inhibitors may be mediated by the activation of intraneuronal "second messenger" proteins which result from the stimulation of postsynaptic receptors (Schatzberg & Nemeroff, 1998).

Receptors for each transmitter come in numerous varieties. Not only are there several types of receptor for each neurotransmitter, but there may be many subtypes. For serotonin, for example, there are seven types of receptors, designated 5-HT$_1$–5-HT$_7$, and seven receptor subtypes, totaling 14 separate receptors (Schatzberg & Nemeroff, 1998). The pace at which receptors are identified has become so dizzying that these figures are likely to be obsolete by the time this paragraph is read.

A pharmacotherapy typically interacts with a receptor in either one of two ways—as an agonist or as an antagonist.[14] When a pharmacotherapy acts as an agonist, it mimics the action of the natural neurotransmitter. When a pharmacotherapy acts as an antagonist, it inhibits, or blocks, the neurotransmitter's action, often by binding to the receptor and preventing the natural transmitter from binding there. An antagonist disrupts the action of the neurotransmitter.

The diversity of receptors presents vast opportunities for drug development. Through rational drug design, pharmacotherapies have become increasingly selective in their actions. Generally speaking, the more selective the pharmacotherapy's action, the more targeted it is to one receptor rather than another, the narrower its spectrum of action, and the fewer the side effects. Conversely, the broader the pharmacotherapy's action, the less targeted to a receptor type or subtype, the broader the effects, and the broader the side effects (Minneman, 1994). However, the interaction among neurotransmitter systems in the brain renders some of the apparent distinctions among medications more apparent than real. Thus, despite differential initial actions on neurotransmitters, both serotonin and norepinephrine reuptake blockers have similar biochemical effects after chronic dosing (Potter et al., 1985).

Complementary and Alternative Treatment

Recent interest in the health benefits of a plethora of natural products has engendered claims related to putative effects on mental health. These have ranged from reports of enhanced memory in people taking the herb, ginseng, to the use of the St. John's wort flowers as an antidepressant (see Chapter 4).

There are major challenges to evaluating the role of complementary and alternative treatments in maintaining mental health or treating mental disorders. In many cases, preparations are not standardized and consist of a variable mixture of substances, any of which may be the active ingredient(s). Purity, bioavailability, amount and timing of doses, and other factors that are standardized for traditional pharmaceutical agents prior to testing cannot be taken for granted with natural products. Current regulations in the United States classify most complementary and alternative treatments as "food supplements," which are not subject to premarketing approval of the Food and Drug Administration.

At present, no conclusions about the role, if any, of complementary and alternative treatments in mental health or illness can be accepted with certainty, as very few claims or studies meet acceptable scientific standards. With funding from government and private industry, controlled clinical trials are under way, including the use of St. John's wort (*Hypericum perforatum*) as a treatment for depression, and omega-3 fatty acids (fish oils) as a mood stabilizer in bipolar depression. In addition, it is important for clinicians and investigators to account for any herbs or natural products being taken by their patients or research subjects that might interact with traditional treatments.

Issues in Treatment

The foregoing section has furnished an overview of the types and nature of mental health treatment. The resounding message, which is echoed throughout this report, is that a range of efficacious treatments is available. The following material deals with four issues surrounding treatment—the placebo response, benefits and risks, the gap between how well treatments work in clinical trials versus in the real world, and the constellation of barriers that hinder people from seeking mental health treatment.

Placebo Response

Recognized since antiquity, the placebo effect refers to the powerful role of patients' attitudes and perceptions that help them improve and recover from health problems. Hippocrates established the therapeutic principle of physicians laying their hands in a reassuring manner to draw on the inner resources of the patient to fight disease. Technically speaking, the placebo effect refers to treatment responses in the placebo group, responses that cannot be explained on the basis of active treatment (Friedman et al., 1996a). A placebo is an inactive treatment, either in the form of an inert pill for studying a new drug treatment or an inactive procedure for studying a psychological therapy. The effects of active treatment are often compared with a control group that receives a pharmacological or psychological placebo.

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[14] There are certainly exceptions to this general rule. Some pharmacotherapies work as partial agonists and partial antagonists simultaneously.

It is not unusual for a placebo effect to be found in up to 50 percent of patients in any study of a medical treatment (Schatzberg & Nemeroff, 1998). For example, about 30 percent of patients typically respond to a placebo in a clinical trial of a new antidepressant (see Chapter 4). The rate is even higher for an antianxiety agent (an anxiolytic) (Schweizer & Rickels, 1997). The placebo effect is of such import that a placebo group or other control group[15] is mandated by the Food and Drug Administration in clinical trials of a new pharmacotherapy to establish its efficacy prior to marketing (Friedman et al., 1996a). If the pharmacotherapy is not statistically superior to the control, efficacy cannot be established. It is somewhat more difficult to fashion an analog of an inert pill in the testing of new and experimental psychological therapies. Psychological studies can employ a "psychological" placebo in the form of a treatment known to be ineffectual. Or they can employ a comparison group, which receives an alternative psychological therapy. Some treatment studies employ both a "psychological" placebo, as well as a comparison group.[16]

The basis of the placebo response is not fully known, but there are thought to be many possible reasons. These reasons, which relate to attributes of the disorder or the disease, the patient, and the treatment setting, include spontaneous remission, personality variables (e.g., social acquiescence), patient expectations, attitudes of and compassion by clinicians, and receiving treatment in a specialized setting (Schweizer & Rickels, 1997). In studies of postoperative pain, the placebo response is mediated by patients' production of endogenous pain-killing substances known as endorphins (Levine et al., 1978).

Benefits and Risks

Throughout this report, currently accepted treatments for mental disorders will be described. Except where otherwise indicated, the efficacy of these interventions has been documented in multiple controlled, clinical trials published in the peer-reviewed literature. In some cases, these have been supplemented by expert consensus reports or practice guidelines.

Most studies of efficacy of specific treatments for mental disorders have been highly structured clinical trials, performed on individuals with a single disorder, in good physical health. While necessary and important, these trials do not always generalize easily to the wider population, which includes many individuals whose mental disorder is accompanied by another mental or somatic disorder and/or alcohol or substance abuse, and who may be taking other medications. Moreover, children, adolescents, and the elderly are excluded from many clinical trials,[17] as are those in certain settings, such as nursing homes. Newer, more generalizable studies are being undertaken to address these shortcomings of the scientific literature (Lebowitz & Rudorfer, 1998).

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[15] When it is unethical to deprive patients of treatment, such as the case with AIDS, conventional treatment is given as the control.

[16] The criteria developed by a division of the American Psychological Association for establishing treatment efficacy call for the experimental treatment to be statistically superior to "pill or psychological placebo or to another treatment" (Chambless et al., 1998).

[17] In March 1998, the NIH issued a policy guideline stating that NIH-funded investigators will be expected to include children in clinical trials, which normally would involve adults only, when there is sound scientific rationale and in the absence of a strong justification to the contrary.

Pending the results of these newer studies, it is important, for clinical decisionmakers to review the current best evidence for the *efficacy* of treatments. People with mental disorders and their health providers should consider all possible options and carefully weigh the pros and cons of each, as well as the possibility of no treatment at all, before deciding upon a course of action. Such an informed consent process entails the calculation of a "benefit-to-risk ratio" for each available treatment option. Most medications or somatic treatments have side effects, for example, but a likelihood of significant clinical benefit often overrides side-effects in support of a treatment recommendation.

Gap Between Efficacy and Effectiveness

Mental health professionals have long observed that treatments work better in the clinical research trial setting as opposed to typical clinical practice settings. The diminished level of treatment effectiveness in real-world settings is so perceptible that it even has a name, the "efficacy-effectiveness gap." Efficacy is the term for what works in the clinical trial setting, and effectiveness is the term for what works in typical clinical practice settings. The efficacy-effectiveness gap applies to both pharmacological therapies and to psychotherapies (Munoz et al., 1994; Seligman, 1995). The gap is not unique to mental health, for it is found with somatic disorders too.

The magnitude of the gap can be surprisingly high. With schizophrenia medications, one review article found that, in clinical trials, the use of traditional antipsychotic medications for schizophrenia was associated with an average annual relapse rate of about 23 percent, whereas the same medications used in clinical practice carried a relapse rate of about 50 percent (Dixon et al., 1995). The magnitude of the gap found in this study may not apply to other medications and other disorders, much less to psychological therapies. Studies of real-world effectiveness are scarce. Yet some degree of gap is widely recognized. The question is, why?

Efficacy studies test whether treatment works under ideal circumstances. They typically exclude patients with other mental or somatic disorders. In the past, they typically have examined relatively homogeneous populations, usually white males. Furthermore, efficacy studies are carried out by highly trained specialists following strict protocols that require frequent patient monitoring. Finally, participation in efficacy studies is often free of charge to patients.

It is not surprising that the reasons commonly cited to explain the discrepancy between efficacy and effectiveness focus on the practicalities and constraints imposed by the real world. In real-world settings, patients often are more heterogeneous and ethnically diverse, are beset by comorbidity (more than one mental or somatic disorder),[18] are often less compliant, and are seen more often in general medical rather than specialty settings; providers are less inclined to adequately monitor and standardize treatment; and cost pressures exist on both patients and providers, depending on the nature of the financing of care (Dixon et al., 1995; Wells & Sturm, 1996). This constellation of real-world constraints appears to explain the gap.

Barriers to Seeking Help

Most people with mental disorders do not seek treatment, according to figures presented in the next section of this chapter and in Chapter 6. This general statement applies to adults and older adults and to parents and guardians who make treatment decisions for children with mental disorders. There is a multiplicity of reasons why people fail to seek treatment for mental disorders but few detailed studies. The barriers to treatment fall under several umbrella categories: demographic factors, patient attitudes toward a service system that often neglects the special needs of racial and ethnic minorities, financial, and organizational.

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[18] Having a second disorder increases the possibility of drug interactions, which may translate into reduced dosing. Comorbidity is discussed throughout this report.

Several demographic factors predispose people against seeking treatment. African Americans, Hispanics (Sussman et al., 1987; Gallo et al., 1995), and poor women (Miranda & Green, 1999) are less inclined than non-Hispanic whites—particularly females—to seek treatment. Common patient attitudes that deter people from seeking treatment are not having the time, fear of being hospitalized, thinking that they could handle it alone, thinking that no one could help, and stigma (being too embarrassed to discuss the problem) (Sussman et al., 1987). Above all, the cost of treatment is the most prevalent deterrent to seeking care, according to a large study of community residents (Sussman et al., 1987). Cost is a major determinant of seeking treatment even among people with health insurance because of inferior coverage of mental health as compared with health care in general. Finally, the organizational barriers include fragmentation of services and lack of availability of services (Horwitz, 1987). Members of racial and ethnic minority groups often perceive that services offered by the existing system do not or will not meet their needs, for example, by taking into account their cultural or linguistic practices. These particular barriers are discussed in greater depth with respect to minority groups (later in this chapter) and with respect to different ages (Chapters 3 to 5).

Demographic, attitudinal, financial, and organizational barriers operate at various points and to various degrees. Seeking treatment is conceived of as a complex process that begins with an individual or parent recognizing that thinking, mood, or behaviors are unusual and severe enough to require treatment; interpreting symptoms as a "medical" or mental health problem; deciding whether or not to seek help and from whom; receiving care; and, lastly, evaluating whether continuation of treatment is warranted (Sussman et al., 1987).

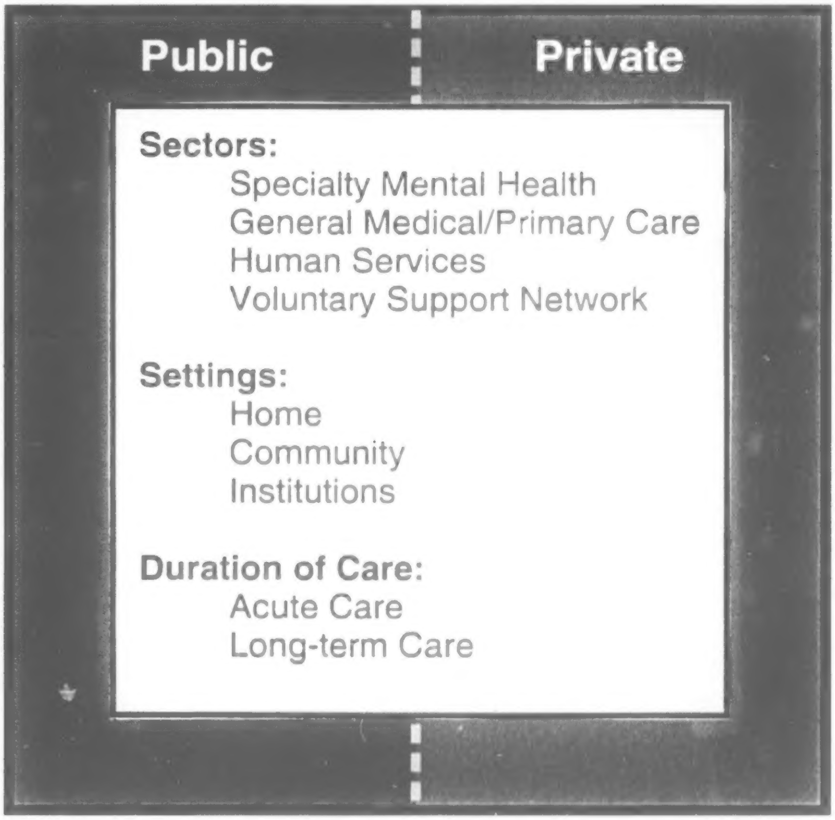
Overview of Mental Health Services

Over the past three centuries, the complex patchwork of mental health services in the United States has become so fragmented that it is referred to as the *de facto mental health system* (Regier et al., 1993b). Its shape has been determined by many heterogeneous factors rather than by a single guiding set of organizing principles. The de facto system has been characterized as having distinct sectors, financing, duration of care, and settings (see Figure 2-4).

The four sectors of the system are the specialty mental health sector, the general medical/primary care sector, the human services sector, and the voluntary support network sector. Specialty mental health services include services provided by specialized mental health professionals (e.g., psychologists, psychiatric nurses, psychiatrists, and psychiatric social workers) and the specialized offices, facilities, and agencies in which they work. Specialty services were designed expressly for the provision of mental health services. The general medical/primary care sector consists of health care professionals (e.g., family physicians, nurse practitioners, internists, pediatricians, etc.) and the settings (i.e., offices, clinics, and hospitals) in which they work. These settings were designed for the full range of health care services, including, but not specialized for, the delivery of mental health services. The human services sector consists of social welfare, criminal justice, educational, religious, and charitable services. The voluntary support network refers to self-help groups and organizations. These are groups devoted to education, communication, and support, all of which extend beyond formal treatment.

Financing of the de facto system refers to the payer of services. The system is often described as being divided into a public (i.e., government) and a private sector. The term "public sector" refers both to services directly operated by government agencies (e.g., state and county mental hospitals) and to services financed with government resources

Figure 2-4. The mental health service system


Public
Private
Sectors:
Specialty Mental Health
General Medical/Primary Care
Human Services
Voluntary Support Network
Settings:
Home
Community
Institutions
Duration of Care:
Acute Care
Long-term Care

(e.g., Medicaid, a Federal-State program for financing health care services for people who are poor and disabled, and Medicare, a Federal health insurance program primarily for older Americans and people who retired early due to disability). Publicly financed services may be provided by private organizations. The term "private sector" refers both to services directly operated by private agencies and to services financed with private resources (e.g., employer-provided insurance).

The duration of care is divided between services for the treatment of acute conditions and those devoted to the long-term care of chronic (i.e., severe and persistent) conditions, such as schizophrenia, bipolar disorder, and Alzheimer's disease. The former, provided in psychiatric hospitals, psychiatric units in general hospitals, and in beds "scattered" in general hospital wards, includes brief treatment-oriented services. Long-term care includes residential care as well as some treatment services. Residential care is often referred to as "custodial," when supervised living predominates over active treatment.

The settings for care and treatment include institutional, community-based, and home-based. The former refers to facilities, particularly public mental hospitals and nursing homes, which usually are seen by patients and families as large, regimented, and impersonal. They often are removed from the community by distance and frequency of contact with friends and family. In contrast, community-based services are close to where patients or clients live. Services are typically provided by community agencies and organizations. Home-based services include informal supports provided in an individual's residence.

Chapter 6 examines the impact of recent changes in financing and organizing services on access and quality of care. Many of these issues also are addressed in Chapters 3 to 5, where they are discussed in the context of care and treatment at each stage of the life cycle. The following material provides general information on current patterns of use and focuses on the historical origins of mental health services.

Overall Patterns of Use

According to recent national surveys (Regier et al, 1993b; Kessler et al., 1996), a total of about 15 percent of the U.S. adult population use mental health services in any given year. Eleven percent receive their services from either the general medical care sector or the specialty mental health sector, in roughly equal proportions. In addition, about 5 percent receive care from the human services sector, and about 3 percent receive care from the voluntary support network. (The overlap across these latter two sectors accounts for these figures totaling more than 15 percent.)

Slightly more than *half* of the 15 percent of the adult population that use mental health services have a diagnosable mental or addictive disorder (8 percent), while the remaining portion has a mental health problem (7 percent). Bearing in mind that 28 percent of the population have a diagnosable mental or substance abuse disorder, only about one-third with a diagnosable mental disorder receives treatment in 1 year (Figure 2-5). In short, this translates to the *majority* of those with a diagnosable mental disorder *not receiving* treatment.

Similarly, about 21 percent of the child and adolescent population use mental health services annually. Nine percent receive care from the health care sector, almost exclusively from the specialty mental health sector. Seventeen percent of the child and adolescent population receive care from the human services sector, mostly in the school system, yet there is much overlap with the health sector (again accounting for the sum being more than 21 percent). The distribution of those who do and do not currently meet diagnostic criteria for a mental disorder is similar to that for adults (Figure 2-6).

History of Mental Health Services

The history of mental health services in the United States has been chronicled by historian Gerald N. Grob in a series of landmark books from which this account is drawn (Grob, 1983, 1991, 1994). The origins of the mental health services system coincide with the colonial settlement of the United States. Individuals with mental illness were cared for at home until urbanization induced state governments to confront a problem that had been relegated largely to families. The states' response was to build institutions, known first as asylums and later as mental hospitals. When the Pennsylvania Hospital opened in Philadelphia in the mid-18th century, it had provisions for individuals with mental illness housed in its basement. Also in the mid-18th century, colonial Virginia was the first state to build an asylum for mentally ill citizens, which it constructed in its capital at Williamsburg. If not cared for at home or in asylums, those with mental illness were likely to be found in jails, almshouses, work houses, and other institutions. By the time of the Revolutionary War, the beginnings were in place for each of the four sectors of the de facto mental health system.

The origins of treatment for mental illness in the general medical/primary care sector can be traced to the Pennsylvania Hospital. The origins of specialty mental health care can be traced to the Williamsburg asylum. Home care, the most common response to mental illness, probably became a part of the voluntary support network, whereas the human services sector was by far the most common organized or institutional response, by placing individuals in almshouses (homes for the poor) and work houses. The first form of treatment—known as "moral treatment"—was not given until the very end of the 18th century, after the Revolutionary War.

Figure 2-5a. Annual prevalence of mental/addictive disorders and services for adults

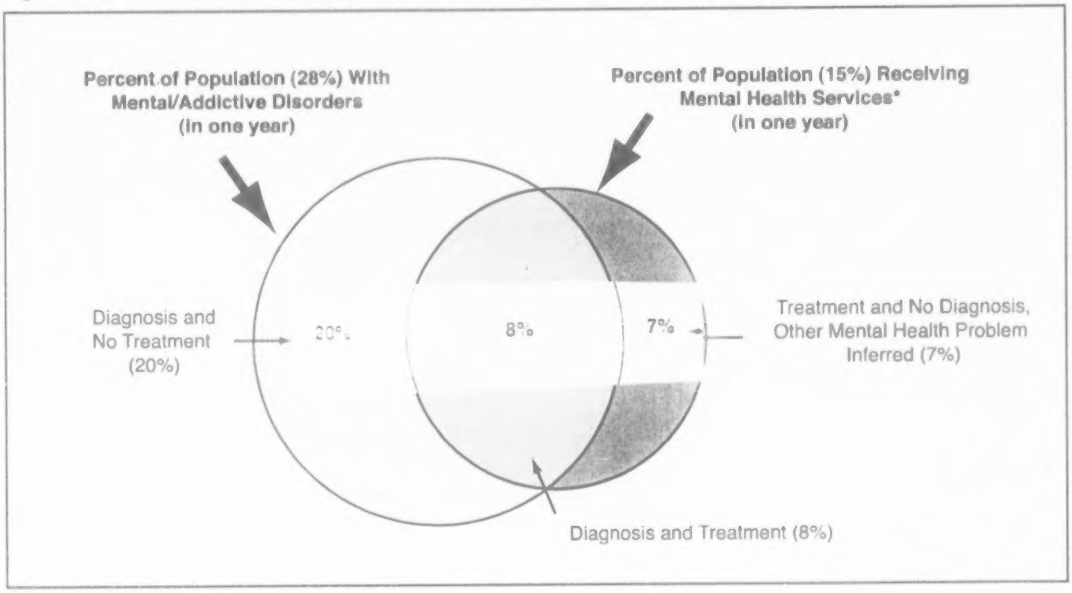
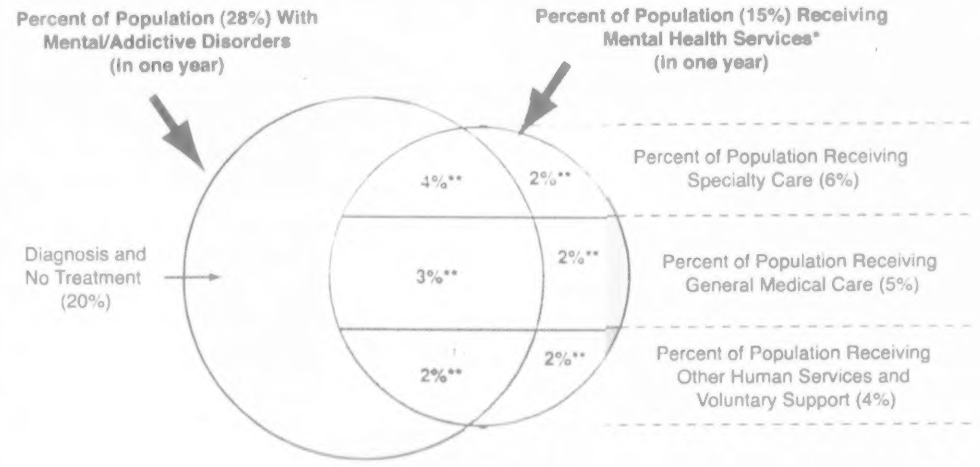

Percent of Population (28%) With
Mental/Addictive Disorders
(in one year)
Percent of Population (15%) Receiving
Mental Health Services*
(in one year)
Diagnosis and
No Treatment
(20%)
20%
8%
7%
Treatment and No Diagnosis,
Other Mental Health Problem
Inferred (7%)
Diagnosis and Treatment (8%)

Figure 2-5b. Annual prevalence of mental/addictive disorders and services for adults


Percent of Population (28%) With
Mental/Addictive Disorders
(in one year)
Percent of Population (15%) Receiving
Mental Health Services*
(in one year)
Diagnosis and
No Treatment
(20%)
4%**
2%**
3%**
2%**
2%**
2%**
Percent of Population Receiving
Specialty Care (6%)
Percent of Population Receiving
General Medical Care (5%)
Percent of Population Receiving
Other Human Services and
Voluntary Support (4%)

* Due to rounding, it appears that 9 percent of the population has a diagnosis and receives treatment. The actual figure is closer to 8 percent, as stated in the text. It also appears that 6 percent of the population receives services but has no diagnosis, due to rounding. The actual total is 7 percent, as stated in the text.

** For those who use more than one sector of the service system, preferential assignment is to the most specialized level of mental health treatment in the system.

Sources: Regier et al., 1993; Kessler et al., 1996

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Figure 2-6a. Annual prevalence of mental/addictive disorders and services for children

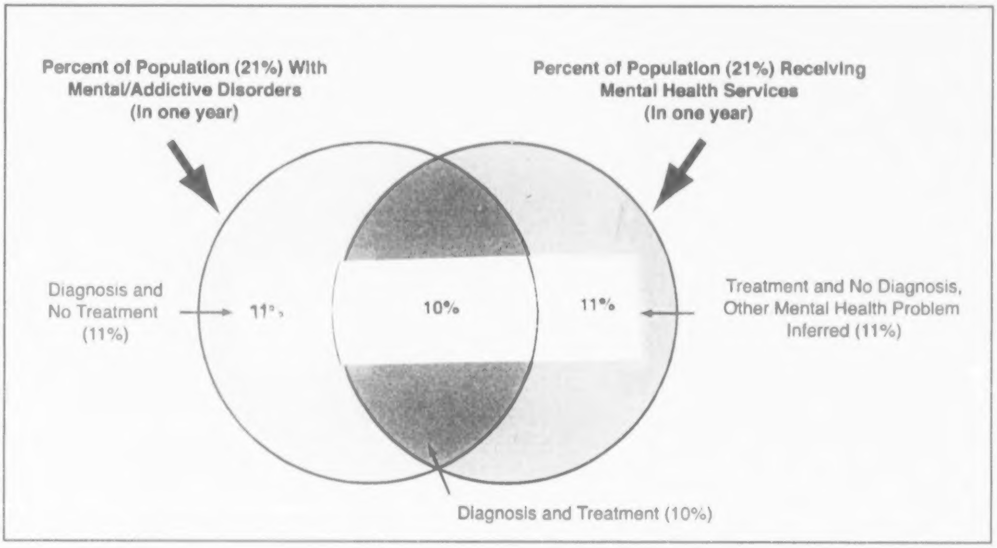
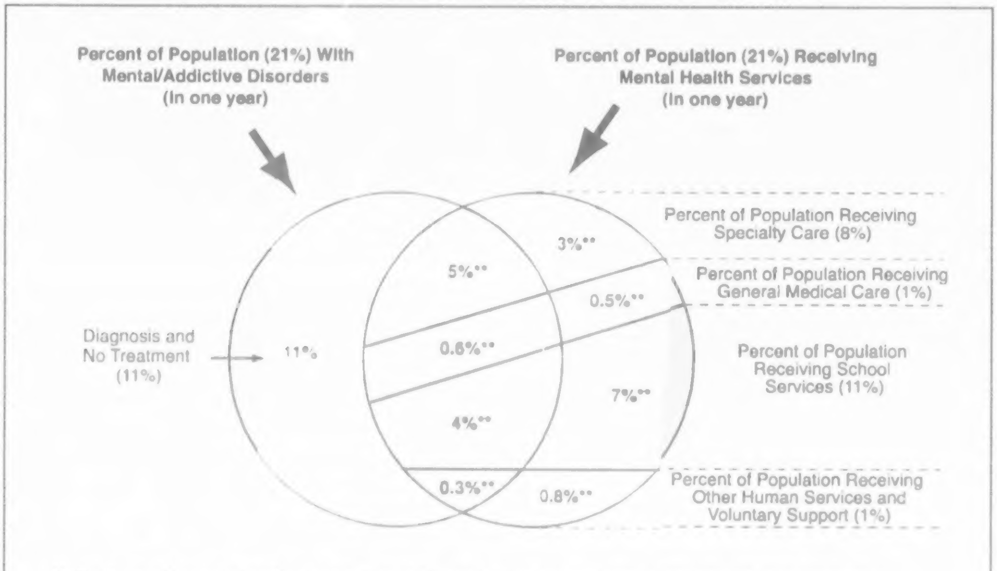

Percent of Population (21%) With Mental/Addictive Disorders (In one year)
Percent of Population (21%) Receiving Mental Health Services (In one year)
Diagnosis and No Treatment (11%)
11%
10%
11%
Treatment and No Diagnosis, Other Mental Health Problem Inferred (11%)
Diagnosis and Treatment (10%)

Figure 2-6b. Annual prevalence of mental/addictive disorders and services for children


Percent of Population (21%) With Mental/Addictive Disorders (In one year)
Percent of Population (21%) Receiving Mental Health Services (In one year)
Diagnosis and No Treatment (11%)
11%
5%**
3%**
0.5%**
0.6%**
4%**
7%**
0.3%**
0.8%**
Percent of Population Receiving Specialty Care (8%)
Percent of Population Receiving General Medical Care (1%)
Percent of Population Receiving School Services (11%)
Percent of Population Receiving Other Human Services and Voluntary Support (1%)

** For those who use more than one sector of the service system, preferential assignment is to the most specialized level of mental health treatment in the system.

Source: Shaffer et al., 1996

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An era of "moral treatment" was introduced from Europe at the turn of the 19th century, representing the first of four reform movements in mental health services in the United States (Morrissey & Goldman, 1984; Goldman & Morrissey, 1985) (Table 2-10).

The first reformers, including Dorothea Dix and Horace Mann, imported the idea that mental illness could be treated by removing the individual to an asylum to receive a mix of somatic and psychosocial treatments in a controlled environment characterized by "moral" sensibilities. The term "moral" had a connotation different from that of today. It meant the return of the individual to reason by the application of psychologically oriented therapy[19] (Grob, 1994). The "moral treatment" period was characterized by the building of private and public asylums. Almost every state had an asylum dedicated to the early treatment of mental illness to restore mental health and to keep patients from becoming chronically ill. Moral treatment accomplished the former objective, but it could not prevent chronicity.

Shortly after the Civil War, the failures of the promise of early treatment were recognized and asylums were built for untreatable, chronic patients. The quality of care deteriorated in public institutions, where overcrowding and underfunding ran rampant. A new reform movement, devoted to "mental hygiene," began late in the 19th century. It combined the newly emerging concepts of public health (which at the time was referred to as "hygiene"), scientific medicine, and social progressivism. Although the states built the public asylums, local government was expected to pay for each episode of care. To avoid the expense, many communities continued to use local almshouses and jails. Asylums could not maintain their budgets, care deteriorated, and newspaper exposés revealed inhuman conditions both in asylums and local welfare institutions. State Care Acts were passed between 1894 and World War I. These acts centralized financial responsibility for the care of individuals with mental illness in every state government. Local government took the opportunity to send everyone with a mental illness, including dependent older citizens, to the state asylums. Dementia was redefined as a mental illness, although only some of the older residents were demented. For the past century the states have carried this responsibility at very low cost, in spite of the magnitude of the task.

The reformers of the "mental hygiene" period, who formed the National Committee on Mental Hygiene (now the National Mental Health Association [NMHA]), called for an expansion of the new science, particularly of neuropathology, in asylums, which were renamed mental hospitals. They also called for "psychopathic hospitals and clinics" to bring the new science to patients in smaller institutions associated with medical schools. They opened several psychiatric units in general hospitals to move mental health care into the mainstream of health care. The mental hygienists believed in the principles of early treatment and expected to prevent chronic mental illness. To support this effort, they advocated for outpatient treatment to identify early cases of mental disorder and to follow discharged inpatients.

Treatments were not effective. Early treatment was no more successful in preventing patients from becoming chronically ill in the early 20th century than it was in the early years of the previous century. At best, the hospitals provided humane custodial care; at worst, they neglected or abused the patients. Length of stay did begin to decline for newly admitted inpatients, but older, long-stay patients filled public asylums. The financial problems and overcrowding deepened during the Depression and during World War II.

Enthusiasm for early interventions, developed by military mental health services during World War II, brought a new sense of optimism about

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[19] According to a student of the originator of moral treatment, Philippe Pinel, "moral treatment is the application of the faculty of intelligence and of the emotions in the treatment of mental alienation" (Grob, 1994).

Table 2-10. Historical reform movements in mental health treatment in the United States

Reform Movement	Era	Setting	Focus of Reform
Moral Treatment	1800–1850	Asylum	Humane, restorative treatment
Mental Hygiene	1890–1920	Mental hospital and clinic	Prevention, scientific orientation
Community Mental Health	1955–1970	Community mental health center	Deinstitutionalization, social integration
Community Support	1975–present	Community support	Mental illness as a social welfare problem (e.g., housing, employment)

Sources: Morrissey & Goldman, 1984; Goldman & Morrissey, 1985

treatment by the middle of the 20th century. Again, early treatment of mental disorders was championed and a new concept was born, "community mental health." The NMHA figured prominently in this reform, along with the Group for the Advancement of Psychiatry. Borrowing some ideas from the mental hygienists and capitalizing on the advent of new drugs for treating psychosis and depression, community mental health reformers argued that they could bring mental health services to the public in their communities. They suggested that long-term institutional care in mental hospitals had been neglectful, ineffective, even harmful. The joint policies of "community care" and "deinstitutionalization" led to dramatic declines in the length of hospital stay and the discharge of many patients from custodial care in hospitals.

Concomitantly, these policies led to the expansion of outpatient services in the community, particularly in federally funded community mental health centers. Federal legislation beginning in the mid-1960s fueled this expansion through grants to centers and then through the inclusion of some (albeit limited) mental health benefits in Medicare and Medicaid. The latter was particularly important, because it stimulated the transfer of many long-term inpatients from public mental hospitals to nursing homes, encouraged the opening of psychiatric units in general hospitals, and ultimately paid for many rehabilitation services for individuals with severe and persistent mental disorders.

The dual policies of community care and deinstitutionalization, however, were implemented without evidence of effectiveness of treatments and without a social welfare system attuned to the needs of hundreds of thousands of individuals with disabling mental illness. Housing, support services, community treatment approaches, vocational opportunities, and income supports for those unable to work were not universally available in the community. Neither was there a truly welcoming spirit of community support for "returning" mental patients. Many discharged mental patients found themselves in welfare and criminal justice institutions, as had their predecessors in earlier eras; some became homeless or lived in regimented residential (e.g., board and care) settings in the community.

The special needs of individuals with severe and persistent mental illness were not being met (General Accounting Office, 1977; Turner & TenHoor, 1978). Early treatment did not prevent disability, although new approaches to treatment would eventually reduce morbidity and improve quality of life. A fourth reform era (1975–present), called the "community support" movement, grew

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directly out of the "community mental health movement." This new reform movement called for an end to viewing and responding to chronic mental disorder only as the object of neglect, by favoring acute treatment and prevention. Reformers advocated for developing "community support systems," with an expanded vision of care and treatment as encompassing the social welfare needs of individuals with disabling mental illness. The emphasis favored the view that individuals could once again become citizens of their community, if given support and access to mainstream resources such as housing and vocational opportunities (Goldman, 1998). At first, mental health treatments were deemphasized in favor of social supports, but newer medications, such as SSRIs and novel antipsychotic drugs, and more effective psychosocial interventions, such as assertive community treatment for schizophrenia (Chapter 4), facilitated the objectives of community support and recovery in the community.

The voluntary support network expanded with an emphasis on "recovery," a concept introduced by service users, or consumers, who began to take an active role in their own care and support and in making policy. From their inception in the late 1970s, family organizations, such as the National Alliance for the Mentally Ill and the Federation of Families, advocated for services for individuals who are most impaired. As discussed later in this chapter, consumers, who also call themselves "survivors," have formed their own networks for support and advocacy and work with other advocacy groups such as the National Mental Health Association and the Bazelon Center for Mental Health Law.

The de facto mental health system is complex because it has metamorphosed over time under the influence of a wide array of factors, including reform movements and their ideologies, financial incentives based on who would pay for what kind of services, and advances in care and treatment technology. Each factor has been important in its own way. The hybrid system that emerged serves many diverse functions. Unfortunately for those individuals with the most complex needs, and who often have the fewest financial resources, the system is fragmented and difficult to use to meet those needs effectively. Efforts at integrating the service system and tailoring it to those with the greatest needs are discussed, by age group, in subsequent chapters of the report. Many problems remain, including the lack of health insurance by 16 percent of the U.S. population, underinsurance for mental disorders even among those who have health insurance, access barriers to members of many racial and ethnic groups, discrimination, and the stigma about mental illness, which is one of the factors that impedes help-seeking behavior.

Overview of Cultural Diversity and Mental Health Services

The U.S. mental health system is not well equipped to meet the needs of racial and ethnic minority populations. Racial and ethnic minority groups are generally considered to be underserved by the mental health services system (Neighbors et al., 1992; Takeuchi & Uehara, 1996; Center for Mental Health Services [CMHS], 1998). A constellation of barriers deters ethnic and racial minority group members from seeking treatment, and if individual members of groups succeed in accessing services, their treatment may be inappropriate to meet their needs.

Awareness of the problem dates back to the 1960s and 1970s, with the rise of the civil rights and community mental health movements (Rogler et al., 1987) and with successive waves of immigration from Central America, the Caribbean, and Asia (Takeuchi & Uehara, 1996). These historical forces spurred greater recognition of the problems that minority groups confront in relation to mental health services.

Research documents that many members of minority groups fear, or feel ill at ease with, the mental health system (Lin et al., 1982; Sussman et al., 1987; Scheffler & Miller, 1991). These groups experience it as the product of white, European culture, shaped by research primarily on white, European populations. They may find only clinicians who represent a white middle-class orientation, with its cultural values and beliefs, as well as its biases, misconceptions, and stereotypes of other cultures.

Research and clinical practice have propelled advocates and mental health professionals to press for "linguistically and culturally competent services" to improve utilization and effectiveness of treatment for different cultures. Culturally competent services incorporate respect for and understanding of, ethnic and racial groups, as well as their histories, traditions, beliefs, and value systems (CMHS, 1998). Without culturally competent services, the failure to serve racial and ethnic minority groups adequately is expected to worsen, given the huge demographic growth in these populations predicted over the next decades (Takeuchi & Uehara, 1996; CMHS, 1998; Snowden, 1999).

This section of the chapter amplifies these major conclusions. It explains the confluence of clinical, cultural, organizational, and financial reasons for minority groups being underserved by the mental health system. The first task, however, is to explain which ethnic and racial groups constitute underserved populations, to describe their changing demographics, and to define the term "culture" and its consequences for the mental health system.

Introduction to Cultural Diversity and Demographics

The Federal government officially designates *four* major racial or ethnic minority groups in the United States: African American (black), Asian/Pacific Islander, Hispanic American (Latino),[20] and Native American/American Indian/Alaska Native/Native Hawaiian (referred to subsequently as "American Indians") (CMHS, 1998). There are many other racial or ethnic minorities and considerable diversity within each of the four groupings listed above. The representation of the four officially designated groups in the U.S. population in 1999 is as follows: African Americans constitute the largest group, at 12.8 percent of the U.S. population; followed by Hispanics (11.4 percent), Asian/Pacific Islanders (4.0 percent), and American Indians (0.9 percent) (U.S. Census Bureau, 1999). Hispanic Americans are among the fastest-growing groups. Because their population growth outpaces that of African Americans, they are projected to be the predominant minority group (24.5 percent of the U.S. population) by the year 2050 (CMHS, 1998).

Racial and ethnic populations differ from one another and from the larger society with respect to culture. The term "culture" is used loosely to denote a common heritage and set of beliefs, norms, and values. The cultures with which members of minority racial and ethnic groups identify often are markedly different from industrial societies of the West. The phrase "cultural identity" specifies a reference group—an identifiable social entity with whom a person identifies and to whom he or she looks for standards of behavior (Cooper & Denner, 1998). Of course, within any given group, an individual's cultural identity may also involve language, country of origin, acculturation,[21] gender, age, class, religious/spiritual beliefs, sexual orientation[22], and physical disabilities (Lu et al., 1995). Many people have multiple ethnic or cultural identities.

The historical experiences of ethnic and minority groups in the United States are reflected in differences in economic, social, and political status. The most measurable difference relates to income. Many racial and ethnic minority groups have limited financial resources. In 1994, families from these groups were at least three times as likely as white families to have incomes placing them below the Federally established poverty line. The disparity is even greater when considering extreme poverty—family incomes at a level less than half of the poverty threshold—and is also large when considering children and older persons (O'Hare, 1996). Although some Asian Americans are somewhat better off financially than other minority groups, they still are more than one and a half times more likely than whites to live in poverty. Poverty disproportionately affects minority women and their children (Miranda & Green, 1999). The effects of poverty are compounded by differences in total value of accumulated assets, or total wealth (O'Hare et al., 1991).

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[20] The term "Latino(a)" refers to all persons of Mexican, Puerto Rican, Cuban, or other Central and South American or Spanish origin (CMHS, 1998).

[21] Acculturation refers to the "social distance" separating members of an ethnic or racial group from the wider society in areas of beliefs and values and primary group relations (work, social clubs, family, friends) (Gordon, 1964). Greater acculturation thus reflects greater adoption of mainstream beliefs and practices and entry into primary group relations.

[22] Research is emerging on the importance of tailoring services to the special needs of gay, lesbian, and bisexual mental health service users (Cabaj & Stein, 1996).

Lower socioeconomic status—in terms of income, education, and occupation—has been strongly linked to mental illness. It has been known for decades that people in the lowest socioeconomic strata are about two and a half times more likely than those in the highest strata to have a mental disorder (Holzer et al., 1986; Regier et al., 1993b). The reasons for the association between lower socioeconomic status and mental illness are not well understood. It may be that a combination of greater stress in the lives of the poor and greater vulnerability to a variety of stressors leads to some mental disorders, such as depression. Poor women, for example, experience more frequent, threatening, and uncontrollable life events than do members of the population at large (Belle, 1990). It also may be that the impairments associated with mental disorders lead to lower socioeconomic status (McLeod & Kessler, 1990; Dohrenwend, 1992; Regier et al., 1993b).

Cultural identity imparts distinct patterns of beliefs and practices that have implications for the willingness to seek, and the ability to respond to, mental health services. These include coping styles and ties to family and community, discussed below.

Coping Styles

Cultural differences can be reflected in differences in preferred styles of coping with day-to-day problems. Consistent with a cultural emphasis on restraint, certain Asian American groups, for example, encourage a tendency not to dwell on morbid or upsetting thoughts, believing that avoidance of troubling internal events is warranted more than recognition and outward expression (Leong & Lau, 1998). They have little willingness to behave in a fashion that might disrupt social harmony (Uba, 1994). Their emphasis on willpower is similar to the tendency documented among African Americans to minimize the significance of stress and, relatedly, to try to prevail in the face of adversity through increased striving (Broman, 1996).

Culturally rooted traditions of religious beliefs and practices carry important consequences for willingness to seek mental health services. In many traditional societies, mental health problems can be viewed as spiritual concerns and as occasions to renew one's commitment to a religious or spiritual system of belief and to engage in prescribed religious or spiritual forms of practice. African Americans (Broman, 1996) and a number of ethnic groups (Lu et al., 1995), when faced with personal difficulties, have been shown to seek guidance from religious figures.[23]

Many people of all racial and ethnic backgrounds believe that religion and spirituality favorably impact upon their lives and that well-being, good health, and religious commitment or faith are integrally intertwined (Taylor, 1986; Priest, 1991; Bacote, 1994; Pargament, 1997). Religion and spirituality are deemed important because they can provide comfort, joy, pleasure, and meaning to life as well as be means to deal with death, suffering, pain, injustice, tragedy, and stressful experiences in the life of an individual or family (Pargament, 1997). In the family/community-centered perception of mental illness held by Asians and Hispanics, religious organizations are viewed as an enhancement or substitute when the family is unable to cope or assist with the problem (Acosta et al., 1982; Comas-Diaz, 1989; Cook & Timberlake, 1989; Meadows, 1997).

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[23] Of the 15 percent of the U.S. population that use mental health services in a given year, about 2.8 percent receive care only from members of the clergy (Larson et al., 1988).

Culture also imprints mental health by influencing whether and how individuals experience the discomfort associated with mental illness. When conveyed by tradition and sanctioned by cultural norms, characteristic modes of expressing suffering are sometimes called "idioms of distress" (Lu et al., 1995). Idioms of distress often reflect values and themes found in the societies in which they originate.

One of the most common idioms of distress is somatization, the expression of mental distress in terms of physical suffering. Somatization occurs widely and is believed to be especially prevalent among persons from a number of ethnic minority backgrounds (Lu et al., 1995). Epidemiological studies have confirmed that there are relatively high rates of somatization among African Americans (Zhang & Snowden, in press). Indeed, somatization resembles an African American folk disorder identified in ethnographic research and is linked to seeking treatment (Snowden, 1998).

A number of idioms of distress are well recognized as culture-bound syndromes and have been included in an appendix to DSM-IV. Among culture-bound syndromes found among some Latino psychiatric patients is *ataque de nervios*, a syndrome of "uncontrollable shouting, crying, trembling, and aggression typically triggered by a stressful event involving family. . . " (Lu et al., 1995, p. 489). A Japanese culture-bound syndrome has appeared in that country's clinical modification of ICD-10 (WHO *International Classification of Diseases*, 10th edition, 1993). *Taijin kyofusho* is an intense fear that one's body or bodily functions give offense to others. Culture-bound syndromes sometimes reflect comprehensive systems of belief, typically emphasizing a need for a balance between opposing forces (e.g., yin/yang, "hot-cold" theory) or the power of supernatural forces (Cheung & Snowden, 1990). Belief in indigenous disorders and adherence to culturally rooted coping practices are more common among older adults and among persons who are less acculturated. It is not well known how applicable DSM-IV diagnostic criteria are to culturally specific symptom expression and culture-bound syndromes.

Family and Community as Resources

Ties to family and community, especially strong in African, Latino, Asian, and Native American communities, are forged by cultural tradition and by the current and historical need to assist arriving immigrants, to provide a sanctuary against discrimination practiced by the larger society, and to provide a sense of belonging and affirming a centrally held cultural or ethnic identity.

Among Mexican-Americans (del Pinal & Singer, 1997) and Asian Americans (Lee, 1998) relatively high rates of marriage and low rates of divorce, along with a greater tendency to live in extended family households, indicate an orientation toward family. Family solidarity has been invoked to explain relatively low rates among minority groups of placing older people in nursing homes (Short et al., 1994).

The relative economic success of Chinese, Japanese, and Korean Americans has been attributed to family and communal bonds of association (Fukuyama, 1995). Community organizations and networks established in the United States include rotating credit associations based on lineage, surname, or region of origin. These organizations and networks facilitate the startup of small businesses.

There is evidence of an African American tradition of voluntary organizations and clubs often having political, economic, and social functions and affiliation with religious organizations (Milburn & Bowman, 1991). African Americans and other racial and ethnic minority groups have drawn upon an extended family tradition in which material and emotional resources are brought to bear from a number of linked households. According to this literature, there is "(a) a high degree of geographical propinquity; (b) a strong sense of family and familial obligation; (c) fluidity of household boundaries, with greater willingness to absorb relatives, both real and fictive, adult and minor, if need arises; (d) frequent interaction with relatives; (e) frequent extended family get-togethers for special occasions and holidays; and (f) a system of mutual aid" (Hatchett & Jackson, 1993, p. 92).

Families play an important role in providing support to individuals with mental health problems. A strong sense of family loyalty means that, despite feelings of stigma and shame, families are an early and important source of assistance in efforts to cope, and that minority families may expect to continue to be involved in the treatment of a mentally ill member (Uba, 1994). Among Mexican American families, researchers have found lower levels of expressed emotion and lower levels of relapse (Karno et al., 1987). Other investigators have demonstrated an association between family warmth and a reduced likelihood of relapse (Lopez et al., in press).

Epidemiology and Utilization of Services

One of the best ways to identify whether a minority group has problems accessing mental health services is to examine their *utilization* of services in relation to their *need* for services. As noted previously, a limitation of contemporary mental health knowledge is the lack of standard measures of "need for treatment" and culturally appropriate assessment tools. Minority group members' needs, as measured indirectly by their prevalence of mental illness in relation to the U.S. population, should be proportional to their utilization, as measured by their representation in the treatment population. These comparisons turn out to be exceedingly complicated by inadequate understanding of the prevalence of mental disorders among minority groups in the United States.[24] Nationwide studies conducted many years ago overlooked institutional populations, which are disproportionately represented by minority groups. Treatment utilization information on minority groups in relation to whites is more plentiful, yet, a clear understanding of health seeking behavior in various cultures is lacking.

The following paragraphs reveal that disparities abound in treatment utilization: some minority groups are underrepresented in the outpatient treatment population while, at the same time, overrepresented in the inpatient population. Possible explanations for the differences in utilization are discussed in a later section.

African Americans

The prevalence of mental disorders is estimated to be higher among African Americans than among whites (Regier et al., 1993a). This difference does not appear to be due to intrinsic differences between the races; rather, it appears to be due to socioeconomic differences. When socioeconomic factors are taken into account, the prevalence difference disappears. That is, the socioeconomic status-adjusted rates of mental disorder among African Americans turn out to be the same as those of whites. In other words, it is the lower socioeconomic status of African Americans that places them at higher risk for mental disorders (Regier et al., 1993a).

African Americans are underrepresented in some outpatient treatment populations, but overrepresented in public inpatient psychiatric care in relation to whites (Snowden & Cheung, 1990;

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[24] In spring 2000, survey field work begins on an NIMH-funded study of the prevalence of mental disorders, mental health symptoms, and related functional impairments in African Americans, Caribbean blacks, and non-Hispanic whites. The study will examine the effects of psychosocial factors and race-associated stress on mental health, and how coping resources and strategies influence that impact. The study will provide a database on mental health, mental disorders, and ethnicity and race. James Jackson, Ph.D., University of Michigan, is principal investigator.

Snowden, in press-b). Their underrepresentation in outpatient treatment varies according to setting, type of provider, and source of payment. The racial gap between African Americans and whites in utilization is smallest, if not nonexistent, in community-based programs and in treatment financed by public sources, especially Medicaid (Snowden, 1998) and among older people (Padgett et al., 1995). The underrepresentation is largest in privately financed care, especially individual outpatient practice, paid for either by fee-for-service arrangements or managed care. As a result, underrepresentation in the outpatient setting occurs more among working and middle-class African Americans, who are privately insured, than among the poor. This suggests that socioeconomic standing alone cannot explain the problem of underutilization (Snowden, 1998).

African Americans are, as noted above, overrepresented in inpatient psychiatric care (Snowden, in press-b). Their rate of utilization of psychiatric inpatient care is about *double* that of whites (Snowden & Cheung, 1990). This difference is even higher than would be expected on the basis of prevalence estimates. Overrepresentation is found in hospitals of all types except private psychiatric hospitals.[25] While difficult to explain definitively, the problem of overrepresentation in psychiatric hospitals appears more rooted in poverty, attitudes about seeking help, and a lack of community support than in clinician bias in diagnosis and overt racism, which also have been implicated (Snowden, in press-b). This line of reasoning posits that poverty, disinclination to seek help, and lack of health and mental health services deemed appropriate, and responsive, as well as community support, are major contributors to delays by African Americans in seeking treatment until symptoms become so severe that they warrant inpatient care.

Finally, African Americans are more likely than whites to use the emergency room for mental health problems (Snowden, in press-a). Their overreliance on emergency care for mental health problems is an extension of their overreliance on emergency care for other health problems. The practice of using the emergency room for routine care is generally attributed to a lack of health care providers in the community willing to offer routine treatment to people without insurance (Snowden, in press-a).

Asian Americans/Pacific Islanders

The prevalence of mental illness among Asian Americans is difficult to determine for methodological reasons (i.e., population sampling). Although some studies suggest higher rates of mental illness, there is wide variance across different groups of Asian Americans (Takeuchi & Uehara, 1996). It is not well known how applicable DSM-IV diagnostic criteria are to culturally specific symptom expression and culture-bound syndromes. With respect to treatment-seeking behavior, Asian Americans are distinguished by extremely low levels at which specialty treatment is sought for mental health problems (Leong & Lau, 1998). Asian Americans have proven less likely than whites, African Americans, and Hispanic Americans to seek care. One national sample revealed that Asian Americans were only a quarter as likely as whites, and half as likely as African Americans and Hispanic Americans, to have sought outpatient treatment (Snowden, in press-a). Asian Americans/Pacific Islanders are less likely than whites to be psychiatric inpatients (Snowden & Cheung, 1990). The reasons for the underutilization of services include the stigma and loss of face over mental health problems, limited English proficiency among some Asian immigrants, different cultural explanations for the problems, and the inability to find culturally competent services. These phenomena are more pronounced for recent immigrants (Sue et al., 1994).

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[25] African Americans are overrepresented among persons undergoing involuntary civil commitment (Snowden, in press-b).

Hispanic Americans

Several epidemiological studies revealed few differences between Hispanic Americans and whites in lifetime rates of mental illness (Robins & Regier, 1991; Vega & Kolody, 1998). A recent study of Mexican Americans in Fresno County, California, found that Mexican Americans born in the United States had rates of mental disorders similar to those of other U.S. citizens, whereas immigrants born in Mexico had lower rates (Vega et al., 1998a). A large study conducted in Puerto Rico reported similar rates of mental disorders among residents of that island, compared with those of citizens of the mainland United States (Canino et al., 1987).

Although rates of mental illness may be similar to whites in general, the prevalence of particular mental health problems, the manifestation of symptoms, and help-seeking behaviors within Hispanic subgroups need attention and further research. For instance, the prevalence of depressive symptomatology is higher in Hispanic women (46%) than men (almost 20%); yet, the known risk factors do not totally explain the gender difference (Vega et al., 1998a; Zunzunegui et al., 1998). Several studies indicate that Puerto Rican and Mexican American women with depressive symptomatology are underrepresented in mental health services and overrepresented in general medical services (Hough et al., 1987; Sue et al., 1991, 1994; Duran, 1995; Jimenez et al., 1997).

Native Americans

American Indians/Alaska Natives have, like Asian Americans and Pacific Islanders, been studied in few epidemiological surveys of mental health and mental disorders. The indications are that depression is a significant problem in many American Indian/Alaska Native communities (Nelson et al., 1992). One study of a Northwest Indian village found rates of DSM-III-R affective disorder that were notably higher than rates reported from national epidemiological studies (Kinzie et al., 1992). Alcohol abuse and dependence appear also to be especially problematic, occurring at perhaps twice the rate of occurrence found in any other population group. Relatedly, suicide occurs at alarmingly high levels (Indian Health Service, 1997). Among Native American veterans, post-traumatic stress disorder has been identified as especially prevalent in relation to whites (Manson, 1998). In terms of patterns of utilization, Native Americans are overrepresented in psychiatric inpatient care in relation to whites, with the exception of private psychiatric hospitals (Snowden & Cheung, 1990; Snowden, in press-b).

Barriers to the Receipt of Treatment

The underrepresentation in outpatient treatment of racial and ethnic minority groups appears to be the result of cultural differences as well as financial, organizational, and diagnostic factors. The service system has not been designed to respond to the cultural and linguistic needs presented by many racial and ethnic minorities. What is unresolved are the relative contribution and significance of each factor for distinct minority groups.

Help-Seeking Behavior

Among adults, the evidence is considerable that persons from minority backgrounds are less likely than are whites *to seek* outpatient treatment in the specialty mental health sector (Sussman et al., 1987; Gallo et al., 1995; Leong & Lau, 1998; Snowden, 1998; Vega et al., 1998a, 1998b; Zhang et al., 1998). This is not the case for emergency department care, from which African Americans are more likely than whites to seek care for mental health problems, as noted above. Language, like economic and accessibility differences, can play an important role in why people from other cultures do not seek treatment (Hunt, 1984; Comas-Diaz, 1989; Cook & Timberlake, 1989; Taylor, 1989).

Mistrust

The reasons why racial and ethnic minority groups are less apt to seek help appear to be best studied among African Americans. By comparison with whites, African Americans are more likely to give the following reasons for not seeking professional help in the face of depression: lack of time, fear of hospitalization, and fear of treatment (Sussman et al., 1987). Mistrust among African Americans may stem from their experiences of segregation, racism, and discrimination (Primm et al., 1996; Priest, 1991). African Americans have experienced racist slights in their contacts with the mental health system, called "microinsults" by Pierce (1992). Some of these concerns are justified on the basis of research, cited below, revealing clinician bias in overdiagnosis of schizophrenia and underdiagnosis of depression among African Americans.

Lack of trust is likely to operate among other minority groups, according to research about their attitudes toward government-operated institutions rather than toward mental health treatment per se. This is particularly pronounced for immigrant families with relatives who may be undocumented, and hence they are less likely to trust authorities for fear of being reported and having the family member deported. People from El Salvador and Argentina who have experienced imprisonment or watched the government murder family members and engage in other atrocities may have an especially strong mistrust of any governmental authority (Garcia & Rodriguez, 1989). Within the Asian community, previous refugee experiences of groups such as Vietnamese, Indochinese, and Cambodian immigrants parallel those experienced by Salvadoran and Argentine immigrants. They, too, experienced imprisonment, death of family members or friends, physical abuse, and assault, as well as new stresses upon arriving in the United States (Cook & Timberlake, 1989; Mollica, 1989).

American Indians' past experience in this country also imparted lack of trust of government. Those living on Indian reservations are particularly fearful of sharing any information with white clinicians employed by the government. As with African Americans, the historical relationship of forced control, segregation, racism, and discrimination has affected their ability to trust a white majority population (Herring, 1994; Thompson, 1997).

Stigma

The stigma of mental illness is another factor preventing African Americans from seeking treatment, but not at a rate significantly different from that of whites. Both African American and white groups report that embarrassment hinders them from seeking treatment (Sussman et al., 1987). In general, African Americans tend to deny the threat of mental illness and strive to overcome mental health problems through self-reliance and determination (Snowden, 1998). Stigma, denial, and self-reliance are likely explanations why other minority groups do not seek treatment, but their contribution has not been evaluated empirically, owing in part to the difficulty of conducting this type of research. One of the few studies of Asian Americans identified the barriers of stigma, suspiciousness, and a lack of awareness about the availability of services (Uba, 1994). Cultural factors tend to encourage the use of family, traditional healers, and informal sources of care rather than treatment-seeking behavior, as noted earlier.

Cost

Cost is yet another factor discouraging utilization of mental health services (Chapter 6). Minority persons are less likely than whites to have private health insurance, but this factor alone may have little bearing on access. Public sources of insurance and publicly supported treatment programs fill some of the gap. Even among working class and middle-class African Americans who have private health insurance, there is underrepresentation of African Americans in outpatient treatment (Snowden, 1998). Yet studies focusing only on poor women, most of whom were members of minority groups, have found cost and lack of insurance to be barriers to treatment (Miranda & Green, 1999). The discrepancies in findings suggest that much research remains to be performed on the relative importance of cost, cultural, and organizational barriers, and poverty and income limitations across the spectrum of racial and ethnic and minority groups.

Clinician Bias

Advocates and experts alike have asserted that bias in clinician judgment is one of the reasons for overutilization of inpatient treatment by African Americans. Bias in clinician judgment is thought to be reflected in overdiagnosis or misdiagnosis of mental disorders. Since diagnosis is heavily reliant on behavioral signs and patients' reporting of the symptoms, rather than on laboratory tests, clinician judgment plays an enormous role in the diagnosis of mental disorders. The strongest evidence of clinician bias is apparent for African Americans with schizophrenia and depression. Several studies found that African Americans were more likely than were whites to be diagnosed with schizophrenia, yet less likely to be diagnosed with depression (Snowden & Cheung, 1990; Hu et al., 1991; Lawson et al., 1994).

In addition to problems of overdiagnosis or misdiagnosis, there may well be a problem of underdiagnosis among minority groups, such as Asian Americans, who are seen as "problem-free" (Takeuchi & Uehara, 1996). The presence and extent of this type of clinician bias are not known and need to be investigated.

Improving Treatment for Minority Groups

The previous paragraphs have documented underutilization of treatment, less help-seeking behavior, inappropriate diagnosis, and other problems that have beset racial and ethnic minority groups with respect to mental health treatment. This kind of evidence has fueled the widespread perception of mental health treatment as being uninviting, inappropriate, or not as effective for minority groups as for whites. The Schizophrenia Patient Outcome Research Team demonstrated that African Americans were less likely than others to have received treatment that conformed to recommended practices (Lehman & Steinwachs, 1998). Inferior treatment outcomes are widely assumed but are difficult to prove, especially because of sampling, questionnaire, and other design issues, as well as problems in studying patients who drop out of treatment after one session or who otherwise terminate prematurely. In a classic study, 50 percent of Asian Americans versus 30 percent of whites dropped out of treatment early (Sue & McKinney, 1975). However, the disparity in dropout rates may have abated more recently (O'Sullivan et al., 1989; Snowden et al., 1989). One of the few studies of clinical outcomes, a pre-versus post-treatment study, found that African Americans fared more poorly than did other minority groups treated as outpatients in the Los Angeles area (Sue et al., 1991). Earlier studies from the 1970s and 1980s had given inconsistent results (Sue et al., 1991).

Ethnopsychopharmacology

There is mounting awareness that ethnic and cultural influences can alter an individual's responses to medications (pharmacotherapies). The relatively new field of ethnopsychopharmacology investigates cultural variations and differences that influence the effectiveness of pharmacotherapies used in the mental health field. These differences are both genetic and psychosocial in nature. They range from genetic variations in drug metabolism to cultural practices that affect diet, medication adherence, placebo effect, and simultaneous use of traditional and alternative healing methods (Lin et al., 1997). Just a few examples are provided to illustrate ethnic and racial differences.

Pharmacotherapies given by mouth usually enter the circulation after absorption from the stomach. From the circulation they are distributed throughout the body (including the brain for psychoactive drugs) and then metabolized, usually in the liver, before they are cleared and eliminated from the body (Brody, 1994). The rate of metabolism affects the amount of the drug in the circulation. A slow rate of metabolism leaves more drug in the circulation. Too much drug in the circulation typically leads to heightened side effects. A fast rate of metabolism, on the other hand, leaves less drug in the circulation. Too little drug in the circulation reduces its effectiveness.

There is wide racial and ethnic variation in drug metabolism. This is due to genetic variations in drug-metabolizing enzymes (which are responsible for breaking down drugs in the liver). These genetic variations alter the activity of several drug-metabolizing enzymes. Each drug-metabolizing enzyme normally breaks down not just one type of pharmacotherapy, but usually several types. Since most of the ethnic variation comes in the form of inactivation or reduction in activity in the enzymes, the result is higher amounts of medication in the blood, triggering untoward side effects.

For example, 33 percent of African Americans and 37 percent of Asians are slow metabolizers of several antipsychotic medications and antidepressants (such as tricyclic antidepressants and selective serotonin reuptake inhibitors) (Lin et al., 1997). This awareness should lead to more cautious prescribing practices, which usually entail starting patients at lower doses in the beginning of treatment. Unfortunately, just the opposite typically had been the case with African American patients and antipsychotic drugs. Clinicians in psychiatric emergency services prescribed more oral doses and more injections of antipsychotic medications to African American patients (Segel et al., 1996). The combination of slow metabolism and overmedication of antipsychotic drugs in African Americans can yield very uncomfortable extrapyramidal[26] side effects (Lin et al., 1997). These are the kinds of experiences that likely contribute to the mistrust of mental health services reported among African Americans (Sussman et al., 1987).

Psychosocial factors also can play an important role in ethnic variation. Compliance with dosing may be hindered by communication difficulties; side effects can be misinterpreted or carry different connotations; some groups may be more responsive to placebo treatment; and reliance on psychoactive traditional and alternative healing methods (such as medicinal plants and herbs) may result in interactions with prescribed pharmacotherapies. The result could be greater side effects and enhanced or reduced effectiveness of the pharmacotherapy, depending on the agents involved and their concentrations (Lin et al., 1997). Greater awareness of ethnopsychopharmacology is expected to improve treatment effectiveness for racial and ethnic minorities. More research is needed on this topic across racial and ethnic groups.

Minority-Oriented Services

Through employment of minority practitioners and the creation of specialized minority-oriented programs, community-based, publicly supported mental health programs have achieved greater minority representation than are found in other mental health settings (Snowden, 1999). Mental health care providers who are themselves from ethnic minority backgrounds are especially likely to treat ethnic minority clients and have been found to enjoy good success in retaining them in treatment (Sue et al., 1991).

The character of the mental health program in which treatment is provided has proven particularly important in encouraging minority mental health service use. Research has shown that programs that specialize in serving identified minority communities have been successful in encouraging minorities to enter and remain in treatment (Yeh et al., 1994; Snowden et al., 1995; Takeuchi et al., 1995; Snowden & Hu, 1996). Modeled on programs successfully targeting groups of recent immigrants and refugees, minority-oriented programs appear to succeed by maintaining active, committed relationships with community institutions and leaders and making aggressive outreach efforts; by maintaining a familiar and welcoming atmosphere; and by identifying and encouraging styles of practice best suited to the problems particular to racial and ethnic minority group members. A challenge for such programs is to meet specialized sociocultural needs for clients from various backgrounds. The track record of minority-oriented programs at improving treatment outcomes is not yet clear for adults but appears to be positive for children and adolescents (Yeh et al., 1994).

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[26] Dystonia (brief or prolonged contraction of muscles), akathisia (an urge to move about constantly), or parkinsonism (tremor and rigidity) (Perry et al., 1997).

There is a specialized system of care for Native Americans that provides mental health treatment. The Indian Health Service (IHS) includes a Mental Health Programs Branch; it offers mental health treatment intended to be culturally appropriate. Urban Indian Health Programs also provide for mental health treatment. The IHS Alcoholism/Substance Abuse Program Branch sponsors services on reservations and in urban communities through contracts with service providers. Most mental health programs in the IHS focus on screening and treatment in primary care settings. Due to budgetary restraints, IHS is able to provide only limited medical, including mental health, coverage of Native American peoples (Manson, 1998).

Many tribes have moved toward self-determination and, as a result, toward assuming direct control of local programs. When surveyed, these tribal health programs reported providing mental health care in a substantial number of instances, although questions remain about the nature and scope of services. Finally, the Department of Veterans Affairs and many state and local authorities provide specialized mental health programming targeting persons of Native American heritage (Manson, 1998). Little is known about the levels and types of care provided under any of these arrangements.

Cultural Competence

Advocates and policymakers have called for all mental health practitioners to be culturally competent: to recognize and to respond to cultural concerns of ethnic and racial groups, including their histories, traditions, beliefs, and value systems (CMHS, 1998).

Cultural competence is one approach to helping mental health service systems and professionals create better services and ensure their adequate utilization by diverse populations (Cross et al., 1989). It is defined as a set of behaviors, attitudes, and policies that come together in a system or agency or among professionals that enables that system, agency, or professionals to work effectively in cross-cultural situations (Cross et al., 1989). This is especially important because most mental health providers are not racial and ethnic minority group members (Hernandez et al., 1998). Using the term "competence" places the responsibility on the mental health services organization and all of its employees, challenging them all to become part of a process of providing culturally appropriate services. This approach emphasizes understanding the importance of culture and building service systems that recognize, incorporate, practice, and value cultural diversity.

There is no single prescribed method for accomplishing cultural competence. It begins with respect, and not taking an ethnocentric perspective about behavior, values, or beliefs. Three possible methods are to render mainstream treatments more inviting and accessible to minority groups through enhanced communication and greater awareness; to select a traditional therapeutic approach according to the perceived needs of the minority group; or to adapt available therapeutic approaches to the needs of the minority group (Rogler et al., 1987). One effort to promote cultural competence has been directed toward mental health services systems and programs. The Center for Mental Health Services has developed, with national input, a preliminary set of performance indicators for "cultural competence" by which service and funding organizations might be judged. Cultural competence in this context includes consultation with cross-cultural experts and training of staff, a capacity to provide services in languages other than English, and the monitoring of caseloads to ensure proportional racial and ethnic representation. The ultimate test of any performance indicator will be documented by improvements in care and treatment of ethnic and racial minorities.

Another response has been to develop guidelines that more directly convey variations believed necessary in the course of clinical practice. An appendix to DSM-IV presents clinicians with an Outline for Cultural Formulation. The guidelines are intended as a supplement to standard diagnosis, for use in multicultural environments and for the provision of a "systematic review of the individual's cultural background, the role of the cultural context in the expression and evaluation of symptoms and dysfunction, and the effect that cultural differences may have on the relationship between the individual and the clinician" (DSM-IV).

The Outline for Cultural Formulation covers several areas. It calls for an assessment of cultural identity, including degree of involvement with alternative cultural reference groups; cultural explanations of illness; cultural factors related to stresses, supports, and level of functioning and disability (e.g., religion, kin networks); differences in culture or social status between patient and clinician and possible barriers (e.g., communication, trust); and overall cultural assessment.

Others have focused attention on the process by which mental health practitioners must engage, assess, and treat patients and on understanding how cultural differences might affect that process (Lopez et al., in press). Viewed from this perspective, the task is to maintain two points of view—that of the cultural group and that of evidence-based mental health practice—and strategically integrate them with the aim of valuing and utilizing culture, context, and practice in a way that promotes mental health.

This capacity has a dual advantage. The practitioner comes to understand the problem as it is experienced and understood by the patient and, in so doing, gains otherwise inaccessible information on personal and social reality for the patient, as well as a sense of trust and credibility. At the same time the practitioner is able to plan for and implement an appropriate intervention. It is through a facility and a willingness to switch from a professional orientation to that of the client and his or her cultural group that the clinician is best able to implement guidelines for cultural competence such as those specified in DSM-IV (Mezzich et al., 1996).

In the end, to be culturally competent is to deliver treatment that is equally effective to all sociocultural groups. The treatments provided must not only be efficacious (based on clinical research), but also effective in community delivery. The delivery of effective treatments is complicated because most research on efficacy has been conducted on predominantly white populations. This suggests the importance of both efficacy and effectiveness studies on racial and ethnic minorities.

At present, there is scant knowledge about treatment effectiveness according to race, culture, or ethnicity (Snowden & Hu, 1996). Rarely has research evaluating standard forms of treatment examined differential effectiveness. In fact, the American Psychological Association's Division of Clinical Psychology Task Force, which tried to identify the efficacy of different psychotherapeutic treatments, could not find a single rigorous study of treatment efficacy published on ethnic minority clients (Chambless et al., 1996). Nor have studies been carried out on the efficacy of proposed cultural adaptations of treatment in comparison with standard alternatives. Only as more knowledge is gained will it become possible to mount a full-fledged and appropriate response to racial and ethnic differences in the provision of mental health care.

Rural Mental Health Services

The differences between rural and urban communities present another source of diversity in mental health services. People in rural America encounter numerous barriers to the receipt of effective services. Some barriers are geographic, created by the problem of delivering services in less densely populated rural areas and even more sparsely populated frontier areas. Some barriers are "cultural," insofar as rural America reflects a range of cultures and life styles that are distinct from urban life. Urban culture and its approach to delivering mental health services dominate mental health services (Beeson et al., 1998).

Rural America is shrinking in size and political influence (Danbom, 1995; Dyer, 1997). As a consequence, rural mental health services do not figure prominently in mental health policy (Ahr & Holcomb, 1985; Kimmel, 1992). Furthermore, rural economies are in decline, and the population is decreasing in most areas (yet expanding rapidly in a few boom areas) (Hannan, 1998). Rural America is no longer a stable or homogeneous environment. The farm crisis of the 1980s unleashed a period of economic hardship and rapid social change, adversely affecting the mental health of the population (Ortega et al., 1994; Hoyt et al., 1995).

Policies and programs designed for urban mental health services often are not appropriate for rural mental health services (Beeson et al., 1998). Beeson and his colleagues (1998) list a host of important differences that should be considered in designing rural mental health services. In an era of specialized services, rural mental health relies heavily on primary medical care and social services. Stigma is particularly intense in rural communities, where anonymity is difficult to maintain (Hoyt et al., 1997). In an era of expanding private mental health services, rural mental health services have been predominantly publicly funded. Consumer and family involvement in advocacy, characteristic of urban and suburban areas, is rare in rural America. The supply of services and providers is limited, so choice is constrained. Mental health services in rural areas cannot achieve certain economies of scale, and some state-of-the art services (e.g., assertive community treatment) are inefficient to deliver unless there is a critical mass of patients. Informal supports and indigenous healers assume more importance in rural mental health care.

Rural mental health concerns are being raised nationally (Rauch, 1997; Ciarlo, 1998; Beeson et al., 1998). Model programs offer new designs for services (Mohatt & Kirwan, 1995), particularly through the integration of mental health and primary care (Bird et al., 1995, 1998; Size, 1998). Newer technology, such as advanced telecommunications in the form of "telemental health," may improve rural access to expertise from professionals located in urban areas (Britain, 1996; La Mendola, 1997; Smith & Allison, 1998). Internet access, videoconferencing, and various computer applications offer an opportunity to enhance the quality of care in rural mental health services.

Overview of Consumer and Family Movements

Since the late 1970s, mental health services continue to be transformed by the growing influence of consumer and family organizations (Lefley, 1996). Through strong advocacy, consumer and family organizations have gained a voice in legislation and policy for mental health service delivery. Organizations representing consumers and family members, though divergent in their historical origins and philosophy, have developed some important, overlapping goals: overcoming stigma and preventing discrimination, promoting self-help groups, and promoting recovery from mental illness (Frese, 1998).

This section covers the history, goals, and impact of consumer and family organizations, whereas the next section covers the process of recovery from mental illness. With literally hundreds of grassroots consumer organizations across the United States, no single organization speaks for all consumers or all families. In fact, even the term "consumer" is not uniformly accepted. Despite the heterogeneity, these organizations typically offer some combination of advocacy and self-help groups (Lefley, 1996).

Many users of mental health services refer to themselves as "consumers." The lexicon is complicated by objections to the term "consumer." To some, being a consumer erroneously signifies that service users have the power to choose services most suitable to their needs. Those who object contend that consumers have neither choices, leverage, nor power to select services. Instead, some consumers refer to themselves as "survivors" or "ex-patients" to denote that they have survived what they experienced as oppression by the mental health system (Chamberlin & Rogers, 1990). This distinction can best be understood in its historical context.

Origins and Goals of Consumer Groups

The consumer movement arose as a protest in the 1970s by former patients of mental hospitals. Their antecedents trace back to the 19th century, when a handful of individuals recovered enough to write exposés expressing their outrage at the indignities and abuses inside mental hospitals. The most persuasive former patient was Clifford Beers, whose classic book, *A Mind That Found Itself* (1908), galvanized the mental hygiene reform movement (Grob, 1994). Beers was among the founders of the National Committee on Mental Hygiene, an advocacy group that later was renamed the National Mental Health Association. This group focuses on linking citizens and mental health professionals in broad-based prevention of mental illness.

With the advent of deinstitutionalization in the 1950s, increasing numbers of former patients of mental hospitals began to forge informal ties in the community. By the 1960s, the civil rights movement inspired former patients to become better organized into what was then coined the mental patients' liberation movement (Chamberlin, 1995). Groups of patients saw themselves as having been rejected by society and robbed of power and control over their lives. To surmount what they saw as persecution, they began to advocate for self-determination and basic rights (Chamberlin, 1990; Frese & Davis, 1997). The posture of these early groups was decidedly militant against psychiatry, against laws favoring involuntary commitment, and often against interventions such as electroconvulsive therapy and antipsychotic medications (Lefley, 1996; Frese, 1998). Groups called Alliance for the Liberation of Mental Patients, the Insane Liberation Front, and Project Release met in homes and churches, drawing their membership from those with firsthand experiences with the mental health system. Largely unfunded, they sustained their membership by providing peer support, education about services in the community, and advocacy to help members access services and to press for reforms (Furlong-Norman, 1988).

The book *On Our Own* (1978) by former patient Judi Chamberlin was a benchmark in the history of the consumer movement. Consumers and others were able to read in the mainstream press what it was like to have experienced the mental health system. For many consumers, reading this book was the beginning of their involvement in consumer organizations (Van Tosh & del Vecchio, in press). Early consumer groups, although geographically dispersed, voluntary, and independent, were linked through the newsletter *Madness Network News*, which continued publication from 1972 to 1986. During the same era, the Conference on Human Rights and Against Psychiatric Oppression was established and met annually from 1973 through 1985 (Chamberlin, 1990). In 1978, early consumer groups gained what they perceived as their first official acknowledgment from the highest levels of government. The President's Commission on Mental Health stated that ". . . groups composed of individuals with mental or emotional problems are being formed all over the United States" (President's Commission on Mental Health, 1978, pp. 14–15). To date, racial and ethnic minority group members are underrepresented within the consumer movement proportionate to their growing representation in the U.S. population. There is a need for more outreach and involvement of consumers representing the special concerns of racial and ethnic minorities.

The advocacy positions of consumers have dealt with the role of involuntary treatment, self-managed care, the role of consumers in research, the delivery of services, and access to mental health services. By 1985, consumer views became so divergent that two groups emerged: The National Association of Mental Patients[27] and the National Mental Health Consumers' Association. The former opposed all forms of involuntary treatment, supported the prohibition of electroconvulsive therapy, and rejected psychotropic medications and hospitalization. The latter organization held more moderate views for improving rather than eschewing the mental health service system (Lefley, 1996; Frese, 1998). Both groups eventually disbanded, but the differences of opinion that they reflected became deeply entrenched.

Self-Help Groups

Self-help refers to groups led by peers to promote mutual support, education, and growth (Lefley, 1996). Self-help is predicated on the belief that individuals who share the same health problem can help themselves and each other to cope with their condition. The self-help approach enjoys a long history, most notably with the formation of Alcoholics Anonymous in 1935 (IOM, 1990). Over time, the self-help approach has been brought to virtually every conceivable health condition.

Since the 1970s, many mental health consumer groups emphasized self-help as well as advocacy (Chamberlin, 1995), although to different degrees. Self-help for recovering mental patients initially emphasized no involvement with mental health professionals. Over time the numbers and types of self-help groups began to flourish and more moderate viewpoints became represented. Self-help groups assume three different postures toward health professionals: the separatist model, the supportive model that allows professionals to aid in auxiliary roles, and partnership models in which professionals act as leaders alongside patients (Chamberlin, 1978; Emerick, 1990). The focus of groups varies, with some groups united on the basis of diagnosis, such as Schizophrenics Anonymous and the National Depressive and Manic-Depressive Association, whereas others are more broad based.

Chamberlin's influential book and another book by former patients, *Reaching Across* (Zinman et al., 1987), explained to consumers how to form self-help groups. These books also extended the concept of self-help more broadly into the provision of consumer-run services as alternatives (as opposed to adjuncts) to mental health treatment (Lefley, 1996).

Programs entirely run by consumers include drop-in centers, case management programs, outreach programs, businesses, employment and housing programs, and crisis services (Long & Van Tosh, 1988; National Resource Center on Homelessness and Mental Illness, 1989; Van Tosh & del Vecchio, in press). Drop-in centers are places for consumers to obtain social support and assistance with problems. Although research is limited, the efficacy of consumer-run services is discussed in Chapter 4.

Consumer positions also are being incorporated into more conventional mental health services—as job coaches and case manager extenders, among others. The rationale for employing consumers in service delivery—in consumer-run or conventional programs—is to benefit those hired and those served. Consumers who are hired obtain employment, enhance self-esteem, gain work experience and skills, and sensitize other service providers to the needs of people with mental disorders. Consumers who are served may be more receptive to care and have role models engaged in their care (Mowbray et al., 1996).

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[27] Later renamed the National Association of Psychiatric Survivors (Chamberlin, 1995).

Accomplishments of Consumer Organizations

Consumer organizations have had measurable impact on mental health services, legislation, and research. One of their greatest contributions has been the organization and proliferation of self-help groups and their impact on the lives of thousands of consumers of mental health services. In 1993, a collaborative survey found that 46 state mental health departments funded 567 self-help groups and agencies for persons with mental disabilities and their family members (National Association of State Mental Health Program Directors, 1993). A nationwide directory lists all 50 states and the District of Columbia as having 235 different mental health consumer organizations (South Carolina SHARE, 1995).

On a systems level, the consumer movement has substantially influenced mental health policy to tailor services to consumer needs. This influence is described by consumers and researchers as "empowerment." A concept from the social sciences, empowerment has come to be defined by mental health researchers as "gaining control over one's life in influencing the organizational and societal structures in which one lives" (Segal et al., 1995).

Consumers are now involved in all aspects of the planning, delivery, and evaluation of mental health services, and in the protection of individual rights. One prominent example is the passage of Public Law 102-321, which established mental health planning councils in every state. Planning councils are required to have membership from consumers and families. Having a planning council so constituted is required for the receipt of Federal block grant funds for mental health services. Other Federal legislation required the establishment of protection and advocacy agencies for patients' rights in every state (Chamberlin & Rogers, 1990; Lefley, 1996).

Another significant development has been the establishment of offices of consumer affairs in many state mental health authorities. Offices of consumer affairs are generally staffed by consumers to support consumer empowerment and self-help in their particular states. A recent survey of state mental health authorities identified 27 states as having paid positions for consumers in central offices (Geller et al., 1998). In 1995, the Federal Center for Mental Health Services hired its first consumer affairs specialist.

The consumer movement also has had a substantial influence on increasing the utilization of consumers as employees in the traditional mental health system, as well as in other human service agencies (Specht, 1988; U.S. Department of Education, 1990; Schlageter, 1990; Interagency Council on the Homeless, 1991). Consumers are being hired at all levels in the mental health system, ranging from case manager aides to management positions in national advocacy organizations, as well as state and Federal governmental agencies.

Finally, consumers continue to be involved in research in several ways: as *participants* of clinical research; as *respondents* who are asked questions about conditions in their life; as *partners* in some aspect of the planning, designing, and conducting of the research project with professional researchers in control; and as *independent researchers* who conduct, analyze the data, and publish the results of the research project (Campbell et al., 1993). The past decade has witnessed the blossoming of a vibrant consumer research agenda and the growing belief that consumer involvement in research and evaluation holds great promise for system reform, quality improvement, and outcome measurement (Campbell et al., 1993; Campbell, 1997). In an effort to enhance the active role of consumers and others in the research process, the National Institute of Mental Health is developing a systematic means of including public participants in the initial review of grant applications in the areas of clinical treatment and services research. This innovation follows up on a recommendation made by the Institute of

Medicine and Committee for the Study of the Future of Public Health (1988).

Family Advocacy

The family movement has experienced spectacular growth and influence since its beginnings in the late 1970s (Lefley, 1996). Although several advocacy and professional organizations speak to the needs of families, the family movement is principally represented by three large organizations. They are the National Alliance for the Mentally Ill (NAMI), the Federation of Families for Children's Mental Health (FFCMH), and the National Mental Health Association (NMHA). NAMI serves families of adults with chronic mental illness, whereas the Federation serves children and youth with emotional, behavioral, or mental disorders. NMHA serves a broad base of family members and other supporters of children and adults with mental disorders and mental health problems. Though the target populations are different, these organizations are similar in their devotion to advocacy, family support, research, and public awareness.

Fragmentation and lack of availability of services were motivating forces behind the establishment of the family movement. Deinstitutionalization, in particular, was a cogent impetus for the formation of NAMI. Deinstitutionalization of the mentally ill left families in the unexpected position of having to assume care for their adult children, a role for which they were ill prepared. Another motivating force behind the family movement was the past tendency by the mental health establishment to blame parents for the mental illness in children (Frese, 1998). The cause of schizophrenia, for example, had been attributed to the "schizophrenogenic mother," who was cold and aloof, according to a reigning but now discredited view of etiology. Similarly, parents were viewed as partly to blame for children with serious emotional or behavioral disturbances (Melaville & Asayesh 1993; Friesen & Stephens, 1998).

NAMI was created as a grassroots organization in 1979 by a small cadre of families in Madison, Wisconsin. Since then, its membership has skyrocketed to 208,000 in all 50 states (NAMI, 1999). NAMI's principal goal is to advocate for improved services for persons with severe and persistent mental illness—for example, schizophrenia and bipolar disorder. Its sole emphasis on the most severely affected consumers distinguishes it from most other consumer and family organizations. Another NAMI goal is to transform public attitudes and reduce stigma by emphasizing the biological basis of serious mental disorders, as opposed to poor parenting (Frese, 1998; NAMI, 1999). Correspondingly, NAMI advocates for intensification of research in the neurosciences. Through state and local affiliates, NAMI operates a network of family groups for self-help and education purposes.

NAMI's accomplishments are formidable. The organization has become a powerful voice for the expansion of community-based services to fulfill the vision of the community support reform movement. NAMI has successfully pressed for Federal legislation for family membership in state mental health planning boards. It is a prime force behind congressional legislation for parity in the financing of mental health services. It also has made substantial inroads in the training of mental health professionals to sensitize them to the predicament of the chronically mentally ill. It has promoted "psychoeducation," specific information to family members, usually in small-group settings, about schizophrenia and about strategies for dealing with relatives with schizophrenia (Lamb, 1994). Finally, NAMI has successfully lobbied for increased Federal research funding, and it has set up private research foundations (Lefley, 1996).

Similarly, advocacy by parents on behalf of children with serious emotional or behavioral disturbances has had a compelling impact. Advocacy for children was electrified by the publication of Jane Knitzer's 1982 book, *Unclaimed Children*; shortly afterward, the

National Mental Health Association (NMHA) issued *Invisible Children* (NMHA, 1983), followed by *A Guide for Advocates to All Systems Failure* (NMHA, 1993). Knitzer chronicled the plight of families in trying to access care from disparate and uncoordinated public agencies, many of which blamed or ignored parents. NMHA, a pioneer in the mental health advocacy field, assumed a pivotal role in strengthening the child mental health movement in the 1980s and early 1990s. Over time, the Federation of Families for Children's Mental Health has become another focal point for families, championing family participation and support in systems of care and access to services. The Federation's chapters across the United States offer self-help, education, and networking (FFCMH, 1999). Through the efforts of these groups and individuals, among the most noteworthy accomplishments of the family movement has been the emergence of family participation in decisionmaking about care for children, one of the decisive historical shifts in service delivery in the past 20 years.

Overview of Recovery

Until recently, some severe mental disorders were generally considered to be marked by lifelong deterioration. Schizophrenia, for instance, was seen by the mental health profession as having a uniformly downhill course (Harding et al., 1992). At the beginning of the 20th century, the leading psychiatrist of the era, Emil Kraepelin, judged the outcome of schizophrenia to be so dismal that he named the disorder "dementia praecox," or premature dementia. Negative conceptions of severe mental illness, perpetuated in textbooks for decades by Kraepelin's original writings, dampened consumers' and families' expectations, leaving them without hope. A turnabout in attitudes came as a result of the consumer movement and self-help activities. They mobilized a shift toward a more positive set of consumer attitudes and self-perceptions. Research provided a scientific basis for and supported a more optimistic view of the possibility of recovering function (Harding et al., 1992). Promoting recovery became a rallying point and common ground for the consumer and family movements (Frese, 1998).

The concept of recovery is having substantial impact on consumers and families, mental health research, and service delivery. Before describing that impact, this section first turns to an introduction and definitions.

Introduction and Definitions

Recovery is a *concept* introduced in the lay writings of consumers beginning in the 1980s. It was inspired by consumers who had themselves recovered to the extent that they were able to write about their experiences of coping with symptoms, getting better, and gaining an identity (Deegan, 1988; Leete, 1989). Recovery also was fueled by longitudinal research uncovering a more positive course for a significant number of patients with severe mental illness (Harding et al., 1992), although findings across several studies were variable (Harrow et al., 1997) (see discussion in Chapter 4).

Recovery is variously called a process, an outlook, a vision, a guiding principle. There is neither a single agreed-upon definition of recovery nor a single way to measure it. But the overarching message is that hope and restoration of a meaningful life are possible, despite serious mental illness (Deegan, 1988; Anthony, 1993; Stocks, 1995; Spaniol et al., 1997). Instead of focusing primarily on symptom relief, as the medical model dictates, recovery casts a much wider spotlight on restoration of self-esteem and identity and on attaining meaningful roles in society.

Written testimonials by former mental patients have appeared for centuries. These writings, according to historian of medicine Roy Porter, "shore up that sense of personhood and identity which they feel is eroded by society and psychiatry" (Porter, 1987). What distinguishes the contemporary wave of writings is their critical mass, organizational backing, and freedom of expression from outside the confines of the institution. Deinstitutionalization, the emergence of community supports and psychosocial rehabilitation, and the growth of the consumer and family advocacy movements all paved the way for recovery to take hold (Anthony, 1993).

The concept of recovery continues to be defined in the writings of consumers (see Figure 2-7). These lay writings offer a range of possible definitions, many of which seek to discover meaning, purpose, and hope from having mental illness (Lefley, 1996). The definitions do not, however, imply full recovery, in which full functioning is restored and no medications are needed. Instead they suggest a journey or process, not a destination or cure (Deegan, 1997). One of the most prominent professional proponents of recovery, William A. Anthony, crystallized consumer writings on recovery with the following definition:

> *. . . a person with mental illness can recover even though the illness is not "cured". . . . [Recovery] is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993).*

It is important to point out that consumers see a distinction between recovery and psychosocial rehabilitation. The latter, which is discussed more extensively in Chapter 4, refers to professional mental health services that bring together approaches from the rehabilitation and the mental health fields (Cook et al., 1996). These services combine pharmacological treatment, skills training, and psychological and social support to clients and families in order to improve their lives and functional capacities. Recovery, by contrast, does not refer to any specific services. Rather, according to the writings of pioneering consumer Patricia Deegan, recovery refers to the "lived experience" of gaining a new and valued sense of self and of purpose (Deegan, 1988).

Figure 2-7. Definitions of recovery from consumer writings

Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again. . . .The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution (Deegan, 1988, p. 15).

One of the elements that makes recovery possible is the regaining of one's belief in oneself (Chamberlin, 1997, p. 9).

Having some hope is crucial to recovery; none of us would strive if we believed it a futile effort. . .I believe that if we confront our illnesses with courage and struggle with our symptoms persistently, we can overcome our handicaps to live independently, learn skills, and contribute to society, the society that has traditionally abandoned us (Leete, 1989, p. 32).

A recovery paradigm is each person's unique experience of their road to recovery. . . .My recovery paradigm included my re-connection which included the following four key ingredients: connection, safety, hope, and acknowledgment of my spiritual self (Long, 1994, p. 4).

To return renewed with an enriched perspective of the human condition is the major benefit of recovery. To return at peace, with yourself, your experience, your world, and your God, is the major joy of recovery (Granger, 1994, p. 10).

Impact of the Recovery Concept

The impact of the recovery concept is felt most by consumers and families. Consumers and families are energized by the message of hope and self-determination. Having more active roles in treatment, research, social and vocational functioning, and personal growth strikes a responsive cord. Consumers' harboring more optimistic attitudes and expectations may improve the course of their illness, based on related research from the field of psychosocial and vocational rehabilitation (see Chapter 4). Yet direct empirical support for the salutary, long-term effect of positive expectations, on both consumers and families, is still in its infancy (Lefley, 1997).

The recovery concept likewise is having a bearing on mental health research and services. Researchers are beginning to study consumer attitudes and behavior to attempt to identify the elements contributing to recovery. Though still at an early stage, research is being driven by consumer perspectives on recovery. Consumers assert that the recovery process is governed by internal factors (their psychological perceptions and expectations), external factors (social supports), and the ability to self-manage care, all of which interact to give them mastery over their lives. The first systematic efforts to define consumer perceptions of recovery was conducted by consumers. The Well-Being Project, sponsored by the California Department of Mental Health, was a landmark effort in which mental health consumers conducted a multifaceted study to define and explore factors promoting or deterring the well-being of persons diagnosed with serious mental illness (Campbell & Schraiber, 1989). Using quantitative survey research, focus groups, and oral histories, Campbell (1993) arrived at a definition of recovery that incorporates "good health, good food, and a decent place to live, all supported by an adequate income that is earned through meaningful work. We need adequate resources and a satisfying social life to meet our desires for comfort and intimacy. Well-being is enriched by creativity, a satisfying spiritual and sexual life, and a sense of happiness" (p. 28).

Through semistructured interviews with consumers about recovery, a subsequent study identified the most common factors associated with their success in dealing with a mental illness. They included medication, community support/case management, self-will/self-monitoring, vocational activity (including school), and spirituality (Sullivan, 1994). Other researchers, also using semistructured interviews, suggested that the rediscovery and reconstruction of a sense of self were important to recovery (Davidson & Strauss, 1992).

These early forays by researchers set the stage for consumer-driven research efforts to identify some of the aspects of recovery. A group of consumers with consultant researchers developed the Empowerment Scale (Rogers et al., 1997). After testing a 28-item scale on members of six self-help programs in six states, factor analysis revealed the underlying dimensions of empowerment to be (1) self-efficacy–self-esteem; (2) power-powerlessness ; (3) community activism; (4) righteous anger; and (5) optimism–control over the future. Other instruments, found to have consistency and construct validity, are the Personal Empowerment Scale, the Organizational Empowerment Scale, and the Extra-Organizational Empowerment Scale (Segal et al., 1995).

Mental health services continue to be refined and shaped by the consumer and recovery emphasis. The most tangible changes in services come from assertive community treatment and psychosocial and vocational rehabilitation, which emphasize an array of approaches to maximize functioning and promote recovery. Consumer interest in self-help and recovery has stimulated the proliferation of interventions for what has been called "illness management" or "self-managed care" for relapse prevention of psychotic symptoms. Illness management training programs now teach individuals to identify early warning signs of relapse and to develop strategies for their prevention. All of these transformations in service delivery and research affirming their benefits are discussed at length in Chapter 4.

Champions of recovery assert that its greatest impact will be on mental health providers and the future design of the service system. They envision services being structured to be recovery-oriented to ensure that recovery takes place. They envision mental health professionals believing in and supporting consumers in their quest to recover. In a groundbreaking article, William A. Anthony described recovery as a guiding vision that "pulls the field of services into the future. A vision is not reflective of what we are currently achieving, but of what we hope for and dream of achieving. Visionary thinking does not raise unrealistic expectations. A vision begets not false promises but a passion for what we are doing."

Conclusions

The past 25 years have been marked by several discrete, defining trends in the mental health field. These have included:

1. The extraordinary pace and productivity of scientific research on the brain and behavior;
2. The introduction of a range of effective treatments for most mental disorders;
3. A dramatic transformation of our society's approaches to the organization and financing of mental health care; and
4. The emergence of powerful consumer and family movements.

Scientific Research. The brain has emerged as the central focus for studies of mental health and mental illness. New scientific disciplines, technologies, and insights have begun to weave a seamless picture of the way in which the brain mediates the influence of biological, psychological, and social factors on human thought, behavior, and emotion in health and in illness. Molecular and cellular biology and molecular genetics, which are complemented by sophisticated cognitive and behavioral science, are preeminent research disciplines in the contemporary neuroscience of mental health. These disciplines are affording unprecedented opportunities for "bottom-up" studies of the brain. This term refers to research that is examining the workings of the brain at the most fundamental levels. Studies focus, for example, on the complex neurochemical activity that occurs within individual nerve cells, or neurons, to process information; on the properties and roles of proteins that are expressed, or produced, by a person's genes; and on the interaction of genes with diverse environmental influences. All of these activities now are understood, with increasing clarity, to underlie learning, memory, the experience of emotion, and, when these processes go awry, the occurrence of mental illness or a mental health problem.

Equally important to the mental health field is "top-down" research; here, as the term suggests, the aim is to understand the broader behavioral context of the brain's cellular and molecular activity and to learn how individual neurons work together in well-delineated neural circuits to perform mental functions.

Effective Treatments. As information accumulates about the basic workings of the brain, it is the task of translational research to transfer new knowledge into clinically relevant questions and targets of research opportunity—to discover, for example, what specific properties of a neural circuit might make it receptive to a safer, more effective medications. To elaborate on this example, theories derived from knowledge about basic brain mechanisms are being wedded more closely to brain imaging tools such as functional Magnetic Resonance Imaging (MRI) that can observe actual brain activity. Such a collaboration would permit investigators to monitor the specific protein molecules intended as the "targets" of a new medication to treat a mental illness or, indeed, to determine how to optimize the effect on the brain of the learning achieved through psychotherapy.

In its entirety, the new "integrative neuroscience" of mental health offers a way to circumvent the antiquated split between the mind and the body that historically has hampered mental health research. It also makes it possible to examine scientifically many of the important psychological and behavioral theories regarding normal development and mental illness that have been developed in years past. The unswerving goal of mental health research is to develop and refine clinical treatments as well as preventive interventions that are based on an understanding of specific mechanisms that can contribute to or lead to illness but also can protect and enhance mental health.

Mental health clinical research encompasses studies that involve human participants, conducted, for example, to test the efficacy of a new treatment. A noteworthy feature of contemporary clinical research is the new emphasis being placed on studying the effectiveness of interventions in actual practice settings. Information obtained from such studies increasingly provides the foundation for services research concerned with the cost, cost-effectiveness, and "deliverability" of interventions and the design—including economic considerations—of service delivery systems.

Organization and Financing of Mental Health Care. Another of the defining trends has been the transformation of the mental illness treatment and mental health services landscapes, including increased reliance on primary health care and other human service providers. Today, the U.S. mental health system is multifaceted and complex, comprising the public and private sectors, general health and specialty mental health providers, and social services, housing, criminal justice, and educational agencies. These agencies do not always function in a coordinated manner. Its configuration reflects necessary responses to a broad array of factors including reform movements, financial incentives based on who pays for what kind of services, and advances in care and treatment technology. Although the hybrid system that exists today serves diverse functions well for many people, individuals with the most complex needs and the fewest financial resources often find the system fragmented and difficult to use. A challenge for the Nation in the near-term future is to speed the transfer of new evidence-based treatments and prevention interventions into diverse service delivery settings and systems, while ensuring greater coordination among these settings and systems.

Consumer and Family Movements. The emergence of vital consumer and family movements promises to shape the direction and complexion of mental health programs for many years to come. Although divergent in their historical origins and philosophy, organizations representing consumers and family members have promoted important, often overlapping goals and have invigorated the fields of research as well as treatment and service delivery design. Among the principal goals shared by much of the consumer movement are to overcome stigma and prevent discrimination in policies affecting persons with mental illness; to encourage self-help and a focus on recovery from mental illness; and to draw attention to the special needs associated with a particular disorder or disability, as well as by age or gender or by the racial and cultural identity of those who have mental illness.

Chapter 2 of the report was written to provide background information that would help persons from outside the mental health field better understand topics addressed in subsequent chapters of the report. Although the chapter is meant to serve as a mental health primer, its depth of discussion supports a range of conclusions:

1. The multifaceted complexity of the brain is fully consistent with the fact that it supports all behavior and mental life. Proceeding from an acknowledgment that all psychological experiences are recorded ultimately in the brain and that all psychological phenomena reflect biological processes, the modern neuroscience of mental health offers an enriched understanding of the inseparability of human experience, brain, and mind.
2. Mental functions, which are disturbed in mental disorders, are mediated by the brain. In the process of transforming human experience into physical events, the brain undergoes changes in its cellular structure and function.

3. Few lesions or physiologic abnormalities define the mental disorders, and for the most part their causes remain unknown. Mental disorders, instead, are defined by signs, symptoms, and functional impairments.
4. Diagnoses of mental disorders made using specific criteria are as reliable as those for general medical disorders.
5. About one in five Americans experiences a mental disorder in the course of a year. Approximately 15 percent of all adults who have a mental disorder in one year also experiences a co-occurring substance (alcohol or other drug) use disorder, which complicates treatment.
6. A range of treatments of well-documented efficacy exists for most mental disorders. Two broad types of intervention include psychosocial treatments—for example, psychotherapy or counseling—and psychopharmacologic treatments; these often are most effective when combined.
7. In the mental health field, progress in developing preventive interventions has been slow because, for most major mental disorders, there is insufficient understanding about etiology (or causes of illness) and/or there is an inability to alter the *known* etiology of a particular disorder. Still, some successful strategies have emerged in the absence of a full understanding of etiology.
8. About 10 percent of the U.S. adult population uses mental health services in the health sector in any year, with another 5 percent seeking such services from social service agencies, schools, religious, or self-help groups. Yet critical gaps exist between those who need service and those who receive service.
9. Gaps also exist between optimally effective treatment and what many individuals receive in actual practice settings.
10. Mental illness and less severe mental health problems must be understood in a social and cultural context, and mental health services must be designed and delivered in a manner that is sensitive to the perspectives and needs of racial and ethnic minorities.
11. The consumer movement has increased the involvement of individuals with mental disorders and their families in mutual support services, consumer-run services, and advocacy. They are powerful agents for changes in service programs and policy.
12. The notion of recovery reflects renewed optimism about the outcomes of mental illness, including that achieved through an individual's own self-care efforts, and the opportunities open to persons with mental illness to participate to the full extent of their interests in the community of their choice.

Mental Health and Mental Illness Across the Lifespan

The Surgeon General's report takes a lifespan approach to its consideration of mental health and mental illness. Three chapters that address, respectively, the periods of childhood and adolescence, adulthood, and later adult life beginning somewhere between ages 55 and 65, capture the contributions of research to the breadth, depth, and vibrancy that characterize all facets of the contemporary mental health field.

The disorders featured in depth in Chapters 3, 4, and 5 were selected on the basis of the frequency with which they occur in our society, and the clinical, societal, and economic burden associated with each. To the extent that data permit, the report takes note of how gender and culture, in addition to age, influence the diagnosis, course, and treatment of mental illness. The chapters also note the changing role of consumers and families, with attention to informal support services (i.e., unpaid services), with which many consumers are comfortable and upon which they depend for information. Persons with mental illness and, often, their families welcome a proliferating array of support services—such as self-help programs, family self-help, crisis services and advocacy—

that help them cope with the isolation, family disruption, and possible loss of employment and housing that may accompany mental disorders. Support services can help to dissipate stigma and to guide patients into formal care as well.

Mental health and mental illness are dynamic, ever-changing phenomena. At any given moment, a person's mental status reflects the sum total of that individual's genetic inheritance and life experiences. The brain interacts with and responds—both in its function and in its very structure—to multiple influences continuously, across every stage of life. At different stages, variability in expression of mental health and mental illness can be very subtle or very pronounced. As an example, the symptoms of separation anxiety are normal in early childhood but are signs of distress in later childhood and beyond. It is all too common for people to appreciate the impact of developmental processes in children, yet not to extend that conceptual understanding to older people. In fact, people continue to develop and change throughout life. Different stages of life are associated with vulnerability to distinct forms of mental and behavioral disorders but also with distinctive capacities for mental health.

Even more than is true for adults, children must be seen in the context of their social environments—that is, family and peer group, as well as that of their larger physical and cultural surroundings. Childhood mental health is expressed in this context, as children proceed along the arc of development. A great deal of contemporary research focuses on developmental processes, with the aim of understanding and predicting the forces that will keep children and adolescents mentally healthy and maintain them on course to become mentally healthy adults. Research also focuses on identifying what factors place some at risk for mental illness and, yet again, what protects some children but not others despite exposure to the *same* risk factors. In addition to studies of normal development and of risk factors, much research focuses on mental disorders in childhood and adolescence and what can be done to prevent or treat these conditions and on the design and operation of service settings best suited to the needs experienced by children.

For about one in five Americans, adulthood—a time for achieving productive vocations and for sustaining close relationships at home and in the community—is interrupted by mental illness. Understanding why and how mental disorders occur in adulthood, often with no apparent portents of illness in earlier years, draws heavily on the full panoply of research conducted under the aegis of the mental health field. In years past, the onset, or occurrence, of mental illness in the adult years, was attributed principally to observable phenomena—for example, the burden of stresses associated with career or family, or the inheritance of a disease viewed to run in a particular family. Such explanations now may appear naive at best.

Contemporary studies of the brain and behavior are racing to fill in the picture by elucidating specific neurobiological and genetic mechanisms that are the platform upon which a person's life experiences can either strengthen mental health or lead to mental illness. It now is recognized that factors that influence brain development prenatally may set the stage for a vulnerability to illness that may lie dormant throughout childhood and adolescence. Similarly, no single gene has been found to be responsible for any specific mental disorder; rather, variations in multiple genes contribute to a disruption in healthy brain function that, under certain environmental conditions, results in a mental illness. Moreover, it is now recognized that socioeconomic factors affect individuals' vulnerability to mental illness and mental health problems. Certain demographic and economic groups are more likely than others to experience mental health problems and some mental disorders. Vulnerability alone may not be sufficient to cause a mental disorder; rather, the causes of most mental disorders lie in some

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combination of genetic and environmental factors, which may be biological or psychosocial.

The fact that many, if not most, people have experienced mental health problems that mimic or even match some of the symptoms of a diagnosable mental disorder tends, ironically, to prompt many people to underestimate the painful, disabling nature of severe mental illness. In fact, schizophrenia, mood disorders such as major depression and bipolar illness, and anxiety often are devastating conditions. Yet relatively few mental illnesses have an unremitting course marked by the most acute manifestations of illness; rather, for reasons that are not yet understood, the symptoms associated with mental illness tend to wax and wane. These patterns pose special challenges to the implementation of treatment plans and the design of service systems that are optimally responsive to an individual's needs during every phase of illness. As this report concludes, enormous strides are being made in diagnosis, treatment, and service delivery, placing the productive and creative possibilities of adulthood within the reach of persons who are encumbered by mental disorders.

Late adulthood is when changes in health status may become more noticeable and the ability to compensate for decrements may become limited. As the brain ages, a person's capacity for certain mental tasks tends to diminish, even as changes in other mental activities prove to be positive and rewarding. Well into late life, the ability to solve novel problems can be enhanced through training in cognitive skills and problem-solving strategies.

The promise of research on mental health promotion notwithstanding, a substantial minority of older people are disabled, often severely, by mental disorders including Alzheimer's disease, major depression, substance abuse, anxiety, and other conditions. In the United States today, the highest rate of suicide—an all-too-common consequence of unrecognized or inappropriately treated depression—is found in older males. This fact underscores the urgency of ensuring that health care provider training properly emphasizes skills required to differentiate accurately the causes of cognitive, emotional, and behavioral symptoms that may, in some instances, rise to the level of mental disorders, and in other instances be expressions of unmet general medical needs.

As the life expectancy of Americans continues to extend, the sheer number—although not necessarily the proportion—of persons experiencing mental disorders of late life will expand, confronting our society with unprecedented challenges in organizing, financing, and delivering effective mental health services for this population. An essential part of the needed societal response will include recognizing and devising innovative ways of supporting the increasingly more prominent role that families are assuming in caring for older, mentally impaired and mentally ill family members.

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CHAPTER 3

CHILDREN AND MENTAL HEALTH

Spanning roughly 20 years, childhood and adolescence are marked by dramatic changes in physical, cognitive, and social-emotional skills and capacities. Mental health in childhood and adolescence is defined by the achievement of expected developmental cognitive, social, and emotional milestones and by secure attachments, satisfying social relationships, and effective coping skills. Mentally healthy children and adolescents enjoy a positive quality of life; function well at home, in school, and in their communities; and are free of disabling symptoms of psychopathology (Hoagwood et al., 1996).

The basic principles for understanding health and illness discussed in the previous chapter apply to children and adolescents, but it is important to underscore the often heard admonition that "children are not little adults." Even more than is true for adults, children must be seen in the context of their social environments, that is, family, peer group, and their larger physical and cultural surroundings. Childhood mental health is expressed in this context, as children proceed through development.

Development, characterized by periods of transition and reorganization, is the focus of much research on children and adolescents. Studies focus on normal and abnormal development, trying to understand and predict the forces that will keep children and adolescents mentally healthy and maintain them on course to become mentally healthy adults. These studies ask what places some at risk for mental illness and what protects some but not others, despite exposure to the same risk factors.

In addition to studies of normal development and of risk factors, much additional research focuses on mental illness in childhood and adolescence and what can be done to prevent or treat it. The science is challenging because of the ongoing process of development. The normally developing child hardly stays the same long enough to make stable measurements. Adult criteria for illness can be difficult to apply to children and adolescents, when the signs and symptoms of mental disorders are often also the characteristics of normal development. For example, a temper tantrum could be an expected behavior in a young child but not in an adult. At some point, however, it becomes clearer that certain symptoms and behaviors cause great distress and may lead to dysfunction of children, their family, and others in their social environment. At these points, it is helpful to consider serious deviations from expected cognitive, social, and emotional development as "mental disorders." Specific treatments and services are available for children and adolescents with such mental disorders, but one cannot forget that these disorders emerge in the context of an ongoing developmental process and shifting relationships within the family and community. These developmental factors must be carefully addressed, if one is to maximize the healthy development of children with mental disorders, promote remediation of associated impairments, and enhance their adult outcomes.

The developmental perspective helps us understand how estimated prevalence rates for mental disorders in children and adolescents vary as a function of the degree of impairment that the child experiences in association with specific symptom patterns. For example, the MECA Study (Methodology for Epidemiology of Mental Disorders in Children and Adolescents) estimated that almost 21 percent of U.S. children ages 9 to 17 had a diagnosable mental or addictive disorder associated with at least minimum impairment (see Table 3-1). When diagnostic criteria

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Table 3-1. Children and adolescents age 9–17 with mental or addictive disorders, combined MECA sample, 6-month (current) prevalence*

	(%)
Anxiety Disorders	13.0
Mood Disorders	6.2
Disruptive Disorders	10.3
Substance Use Disorders	2.0
Any Disorder	20.9

* Disorders include diagnosis-specific impairment and Child Global Assessment Scale < 70 (mild global impairment)

Source: Shaffer et al., 1996a

required the presence of *significant* functional impairment, estimates dropped to 11 percent. This estimate translates into a total of 4 million youth who suffer from a major mental illness that results in significant impairments at home, at school, and with peers. Finally, when *extreme* functional impairment is the criterion, the estimates dropped to 5 percent.

Given the process of development, it is not surprising that these disorders in some youth are known to wax and wane, such that some afflicted children improve as development unfolds, perhaps as a result of healthy influences impinging on them. Similarly, other youth, formerly only "at risk," may develop full-blown forms of disorder, as severe and devastating in their impact on the youth and his or her family as are the analogous conditions that affect adults. Characterizing such disorders as relatively unchangeable underestimates the potential beneficial influences that can redirect a child whose development has gone awry. Likewise, characterizing children with mental disorders as "only" the victims of negative environmental influences that might be fixed if societal factors were just changed runs the risk of underestimating the severity of these conditions and the need for focused, intensive clinical interventions for suffering children and adolescents. Thus, the science of mental health in childhood and adolescence is a complex mix of the study of development and the study of discrete conditions or disorders. Both perspectives are useful. Each alone has its limitations, but together they constitute a more fully informed approach that spans mental health and illness *and* allows one to design developmentally informed strategies for prevention and treatment.

Normal Development

Development is the lifelong process of growth, maturation, and change that unfolds at the fastest pace during childhood and adolescence. An appreciation of normal development is crucial to understanding mental health in children and adolescents and the risks they face in maintaining mental health. Distortions in the process of development may lead to mental disorders. This section deals with the normal development of understanding (cognitive development) in young children and the development of social relationships and temperament.

Theories of Development

Historically, the changes that take place in a child's psyche between birth and adulthood were largely ignored. Child development first became a subject of serious inquiry at the beginning of this century but was mostly viewed from the perspective of mental disorders and from the cultural mainstream of Europe and white America. Some of the "grand theories" of child development, such as that propounded by Sigmund Freud, grew out of this focus, and they unquestionably drew attention to the importance of child development in laying the foundation for adult mental health. Even those theories that resulted from the observation of healthy children, such as Piaget's theory of cognitive development, paid little attention to the relationship between the development of the "inner self" and the environment into which the individual was placed. In contrast, the interaction of an individual with the environment was central to the school of thought known as behaviorism.

Theories of normal development, introduced in Chapter 2, are presented briefly below, because they form the basis of many current approaches to understanding and treating mental illness and mental health problems in children and adults. These theories have not achieved the broader objective of explaining how children grow into healthy adults. More study and perhaps new theories will be needed to improve our ability to guide healthy child-rearing with scientific evidence.

Development Viewed as a Series of Stages

Freud and the psychoanalyst Erik Erikson proposed a series of stages of development reflecting the attainment of biological objectives. The stages are expressed in terms of functioning as an individual and with others—within the family and the broader social environment (particularly in Erikson's theories) (see Chapter 2). Although criticized as unscientific and relevant primarily to the era and culture in which they were conceived, these theories introduced the importance of thinking developmentally, that is, of considering the ever-changing physical and psychological capacities and tasks faced by people as they age. They emphasized the concept of "maturation" and moving through the stages of life, adapting to changing physical capacities and new psychological and social challenges. And they described mental health problems associated with failure to achieve milestones and objectives in their developmental schemes.

These theories have guided generations of psychodynamic therapists and child development experts. They are important to understand as the underpinnings of many therapeutic approaches, such as interpersonal therapy, some of which have been evaluated and found to be efficacious for some conditions. By and large, however, these theories have rarely been tested empirically.

Intellectual Development

The Swiss psychologist Jean Piaget also developed a stage-constructed theory of children's intellectual development. Piaget's theory, based on several decades' observations of children (Inhelder & Piaget, 1958), was about how children gradually acquire the ability to understand the world around them through active engagement with it. He was the first to recognize that infants take an active role in getting to know their world and that children have a different understanding of the world than do adults. The principal limitations of Piaget's theories are that they are descriptive rather than explanatory. Furthermore, he neglected variability in development and temperament and did not consider the crucial interplay between a child's intellectual development and his or her social experiences (Bidell & Fischer, 1992).

Behavioral Development

Other approaches to understanding development are less focused on the stages of development. Behavioral psychology focused on observation and measurement, explaining development in terms of responses to stimuli, such as rewards. Not only did the theories of the early pioneers (e.g., Pavlov, Watson, and Skinner) generate a number of valuable treatments, but their focus on precise description set the stage for current programs of research based on direct observation. Social learning theory (Bandura, 1977) emphasized role models and their impact on children and adolescents as they develop. Several important clinical tools came out of behaviorism (e.g., reinforcement and behavior modification) and social learning theory (cognitive-behavioral therapy). Both treatment approaches are used effectively with children and adolescents.

Social and Language Development

Parent-Child Relationships

It is common knowledge that infants and, for the most part, their principal caretakers typically develop a close bond during the first year of life, and that in the second year of life children become distressed when they are forcibly separated from their mothers. However, the clinical importance of these bonds was not fully appreciated until John Bowlby introduced the concept of *attachment* in a report on the effects of maternal deprivation (Bowlby, 1951). Bowlby (1969) postulated that the pattern of an infant's early attachment to parents would form the basis for all later social relationships. On the basis of his experience with disturbed children, he hypothesized that, when the mother was unavailable or only partially available during the first months of the child's life, the attachment process would be interrupted, leaving enduring emotional scars and predisposing a child to behavioral problems.

A mother's bond with her child often starts when she feels fetal movements during pregnancy. Immediately after birth, most, but by no means all, mothers experience a surge of affection that is followed by a feeling that the baby belongs to them. This experience may not occur at all or be delayed under conditions of addiction or postnatal depression (Robson & Kumar, 1980; Kumar, 1997). Yet, like all enduring relationships, it seems that the relationship between mother and child develops gradually and strengthens over time. Some infants who experience severe neglect in early life may develop mentally and emotionally without lasting consequences, for example, if they are adopted and their adoptive parents provide sensitive, stable, and enriching care, or if depressed or substance-abusing mothers recover fully (Koluchova, 1972; Dennis, 1973; Downey & Coyne, 1990). Unfortunately, however, early neglect is all too often the precursor of later neglect. When the child remains subject to deprivation, inadequate or insensitive care, lack of affection, low levels of stimulation, and poor education over long periods of time, later adjustment is likely to be severely compromised (Dennis, 1973; Curtiss, 1977).

In general, it appears that the particular caregiver with whom infants interact (i.e., biological mother or another) is less important for the development of good social relationships than the fact that infants interact over a period of time with someone who is familiar and sensitive (Lamb, 1975; Bowlby, 1988). One of the problems in the later development of children who experience early institutionalization or significant neglect is that there may have been no opportunities for the caretakers and the infants to establish strong and mutual attachments in a reciprocating relationship.

Origins of Language

Recent research has established that successful use of language and communication is a cornerstone of childhood mental health. Not only are strong language capabilities critical to the development of such skills as listening and speaking, but they also are fundamental to the acquisition of proficient reading and writing abilities. In turn, children with a variety of speech and language impediments are at increasing risk as their language abilities fall behind those of their peers. Caretaker and baby start to communicate with each other vocally as well as visually during the first months of life. Many, but not all, developmental psychologists believe that this early pattern of mother-infant reciprocity and interchange is the basis on which subsequent language and communication develop. Various theorists have attempted to explain the relations between language and cognitive development (Vygotsky, 1962; Chomsky, 1965, 1975, 1986; Bruner, 1971; Luria, 1971), but no single theory has achieved preeminence. While a number of theories address language development from different perspectives, all theories suggest that language development depends on both biological and socio-environmental factors. It is clear that language competence is a critical aspect of children's mental health.

Relationships With Other Children

To be healthy, children must form relationships not only with their parents, but also with siblings and with peers. Peer relationships change over time. In the toddler period, children's social skills are very limited; they spend most of their time playing side by side rather than with each other in a give-and-take fashion.

As children grow, their abilities to form close relationships become highly dependent on their social skills. These include an ability to interpret and understand other children's nonverbal cues, such as body language and pitch of voice. Children whose social skills develop optimally respond to what other children say, use eye contact, often mention the other child's name, and may use touch to get attention. If they want to do something that other children oppose, they can articulate the reasons why their plan is a good one. They can suppress their own wishes and desires to reach a compromise with other children and may be willing to change—at least in the presence of another child—a stated belief or wish. When they are with a group of children they do not know, they are quiet but observant until they have a feeling for the structure and dynamics of the group (Coie & Kuperschmidt, 1983; Dodge, 1983; Putallaz, 1983; Dodge & Feldman, 1990; Kagan et al., 1998).

In contrast, children who lack such skills tend to be rejected by other children. Commonly, they are withdrawn, do not listen well, and offer few if any reasons for their wishes; they rarely praise others and find it difficult to join in cooperative activities (Dodge, 1983). They often exhibit features of oppositional defiant or conduct disorder, such as regular fighting, dominating and pushing others around, or being spiteful (Dodge et al., 1990). Social skills improve with opportunities to mix with others (Bridgeman, 1981). In recent years, knowledge of the importance of children's acquisition of social skills has led to the development and integration of social skills training components into a number of successful therapeutic interventions.

Temperament

During the past two decades, as psychologists began to view the child less as a passive recipient of environmental input but rather as an active player in the process, the importance of temperament has become better appreciated (Plomin, 1986). Temperament is defined as the repertoire of traits with which each child is born; this repertoire determines how people react to the world around them. Such variations in characteristics were first described systematically by Anna Freud from her observations of children orphaned by the ravages of World War II. She noticed that some children were affectionate, some wanted to be close but were too shy to approach adults, and some were difficult because they were easily angered and frustrated (A. Freud, 1965).

The first major longitudinal observations on temperament were begun in the 1950s by Thomas and Chess (1977). They distinguished 10 aspects of temperament, but there appear to be many different ways to describe temperamental differences (Goldsmith et al., 1987). Although there is some continuity in temperamental qualities throughout the life span (Chess & Thomas, 1984; Mitchell, 1993), temperament is often modified during development, particularly by the interaction with the caregiver. For example, a timid child can become bolder with the help of parental encouragement (Kagan, 1984, 1989). Some traits of temperament, such as attention span, goal orientation, lack of distractibility, and curiosity, can affect cognitive functioning because the more pronounced these traits are, the better a child will learn (Campos et al., 1983). Of note, it is not always clear whether extremes of temperament should be considered within the spectrum of mental disorder (for example, shyness or anxiety) or whether certain forms of temperament might predispose a child to the development of certain mental disorders.

Developmental Psychopathology

Current Developmental Theory Applied to Child Mental Health and Illness

A number of central concepts and guiding assumptions underpin our current understanding of children's mental health and illness. These have been variously defined by different investigators (Sroufe & Rutter, 1984; Cicchetti & Cohen, 1995; Jensen, 1998), but by and large these tenets are based on the premise that psychopathology in childhood arises from the complex, multilayered interactions of specific characteristics of the child (including biological, psychological, and genetic factors), his or her environment (including parent, sibling, and family relations, peer and neighborhood factors, school and community factors, and the larger social-cultural context), and the specific manner in which these factors interact with and shape each other over the course of development. Thus, an understanding of a child's particular history and past experiences (including biologic events affecting brain development) is essential to unravel the why's and wherefore's of a child's particular behaviors, both normal and abnormal.

While this principle assumes developmental continuities, to the extent that early experiences are "brought forward" into the current behavior, it is also important to consider developmental discontinuities, where qualitative shifts in the child's biological, psychological, and social capacities may occur. These may not be easily discerned or predicted ahead of time and may reflect the emergence of new capacities (or incapacities) as the child's psychological self, brain, and social environment undergo significant reorganization.

A second precept underlying an adequate understanding of children's mental health and illness concerns the innate tendencies of the child to adapt to his or her environment. This principle of adaptation incorporates and acknowledges children's "self-righting" and "self-organizing" tendencies; namely, that a child within a given context naturally adapts (as much as possible) to a particular ecological niche, or when necessary, modifies that niche to get needs met. When environments themselves are highly disordered or pathological, children's adaptations to such settings may also be pathologic, especially when compared with children's behaviors within more healthy settings. This principle underscores the likelihood that some (but not all) "pathologic" behavioral syndromes might be best characterized as adaptive responses when the child or adolescent encounters difficult or adverse circumstances. Notably, this ability to adapt behaviorally is reflected at multiple levels, including the level of brain and nervous system structures (sometimes called neuroplasticity).

A third consideration that guides both research-based and clinical approaches to understanding child mental health and illness concerns the importance of age and timing factors. For example, a behavior that may be quite normal at one age (e.g., young children's distress when separated from their primary caretaking figure) can be an important symptom or indicator of mental illness at another age. Similarly, stressors or risk factors may have no, little, or profound impact, depending on the age at which they occur and whether they occur alone or with other accumulated risk factors.

A fourth premise underpinning an adequate understanding of children's mental health and illness concerns the importance of the child's context. Perhaps the most important context for developing children is their caretaking environment. Research with both humans and animals has demonstrated that gross disruptions in this critical parameter have immediate and long-term effects, not just on the young organism's later social-emotional development but also on physical health, long-term morbidity and mortality, later parenting practices, and even behavioral outcomes of its offspring. Moreover, context may play a role in the definition of what actually constitutes psychopathology or health. The same behavior in one setting or culture might be acceptable and even "normative," whereas it may be seen as pathological in another.

Yet another principle central to understanding child mental health and illness is that normal and abnormal developmental processes are often separated only by differences of degree. Thus, supposed differences between normal and abnormal behavior may be better understood by taking into account the differences in the amount or degree of the particular behavior, or the degree of exposure to a particular risk factor. Frequently, no sharp distinctions can be made.

The virtue of these developmental considerations when applied to children is that (a) they enable a broader, more informed search for factors related to the onset of, maintenance of, and recovery from abnormal forms of child behavior; (b) they help move beyond static diagnostic terms that tend to reduce the behaviors of a complex, developing, adapting, and feeling child to an oversimplified diagnostic term; (c) they offer a new perspective on potential targets for intervention, whether child-focused or directed toward environmental or contextual factors; and (d) they highlight the possibility of important timing considerations: windows of opportunity during a child's development when preventive or treatment interventions may be especially effective.

In the sections that follow, these considerations will help the reader understand the important differences from chapters focusing principally on adults, as well as the unique opportunities for intervention that occur because of these differences.

Overview of Risk Factors and Prevention

Current approaches to understanding the etiology of mental disorders in childhood are driven by empirical advances in neuroscience and behavioral research rather than by theories. Epidemiological research on the factors that make children vulnerable to mental illness is important for several reasons: delineating the range of risk factors for particular mental disorders helps to understand their etiology; the populations most at risk can be identified; understanding the relative strength of different risk factors allows for the design of appropriate prevention programs for children in different contexts; and resources can be better allocated to intervene so as to maximize their effectiveness.

Risk Factors

There is now good evidence that *both* biological factors and adverse psychosocial experiences during childhood influence—but not necessarily "cause"—the mental disorders of childhood. Adverse experiences may occur at home, at school, or in the community. A stressor or risk factor may have no, little, or a profound impact, depending on individual differences among children and the age at which the child is exposed to it, as well as whether it occurs alone or in association with other risk factors. Although children are influenced by their psychosocial environment, most are inherently resilient and can deal with some degree of adversity. However, some children, possibly those with an inherent biological vulnerability (e.g., genes that convey susceptibility to an illness), are more likely to be harmed by an adverse environment, and there are some environmental adversities, especially those that are long-standing or repeated, that seem likely to induce a mental disorder in all but the hardiest of children. A recent analysis of risk factors by Kraemer and colleagues (1997) has provided a useful framework for differentiating among categories of risk and may help point this work in a more productive direction.

Risk factors for developing a mental disorder or experiencing problems in social-emotional development include prenatal damage from exposure to alcohol, illegal drugs, and tobacco; low birth weight; difficult temperament or an inherited predisposition to a mental disorder; external risk factors such as poverty, deprivation, abuse and neglect; unsatisfactory relationships; parental mental health disorder; or exposure to traumatic events.

Biological Influences on Mental Disorders

It seems likely that the roots of most mental disorders lie in some combination of genetic and environmental factors—the latter may be biological or psychosocial (Rutter et al., 1999). However, increasing consensus has emerged that biologic factors exert especially pronounced influences on several disorders in particular, including pervasive developmental disorder (Piven & O'Leary, 1997), autism (Piven & O'Leary, 1997), and early-onset schizophrenia (McClellan & Werry, in press). It is also likely that biological factors play a large part in the etiology of social phobia (Pine, 1997), obsessive-compulsive disorder (Leonard et al., 1997), and other disorders such as Tourette's disorder (Leckman et al., 1997).

Two important points about biological factors should be borne in mind. The first is that biological influences are not necessarily synonymous with those of genetics or inheritance. Biological abnormalities of the central nervous system that influence behavior, thinking, or feeling can be caused by injury, infection, poor nutrition, or exposure to toxins, such as lead in the environment. These abnormalities are not inherited. Mental disorders that are most likely to have genetic components include autism, bipolar disorder, schizophrenia, and attention-deficit/hyperactivity disorder (ADHD) (National Institute of Mental Health [NIMH], 1998). Second, it is erroneous to assume that biological and environmental factors are independent of each other, when in fact they interact. For example, traumatic experiences may induce biological changes that persist. Conversely, children with a biologically based behavior may modify their environment. For example, low-birth-weight infants who have sustained brain damage, and thereby become excessively irritable, may change the behavior of caretakers in a way that adversely affects the caretaker's ability to provide good care. Thus, it is now well documented that a number of biologic risk factors exert important effects on brain structure and function and increase the likelihood of subsequently developing mental disorders. These well-established factors include intrauterine exposure to alcohol or cigarette smoke (Nichols & Chen, 1981), perinatal trauma (Whitaker et al., 1997), environmental exposure to lead (Needleman et al., 1990), malnutrition of pregnancy, traumatic brain injury, nonspecific forms of mental retardation, and specific chromosomal syndromes.

Psychosocial Risk Factors

A landmark study on risks from the environment (Rutter & Quinton, 1977) showed that several factors can endanger a child's mental health. Dysfunctional aspects of family life such as severe parental discord, a parent's psychopathology or criminality, overcrowding, or large family size can predispose to conduct disorders and antisocial personality disorders, especially if the child does not have a loving relationship with at least one of the parents (Rutter, 1979). Economic hardship can indirectly increase a child's risk of developing a behavioral disorder because it may cause behavioral problems in the parents or increase the risk of child abuse (Dutton, 1986; Link et al., 1986; Wilson, 1987; Schorr, 1988). Exposure to acts of violence also is identified as a possible cause of stress-related mental health problems (Jenkins & Bell, 1997). Studies point to poor caregiving practices as being a risk factor for children of depressed parents (Zahn-Waxler et al., 1990).

The quality of the relationship between infants or children and their primary caregiver, as manifested by the security of attachment, has long been felt to be of paramount importance to mental health across the life span. In this regard, the relationship between maternal problems and those factors in children that predispose them to form insecure attachments, particularly young infants' and toddlers' security of attachment and temperament style and their impact on the development of mood and conduct disorders, is of great interest to researchers. Many investigators have taken the view that the nature and the outcome of the attachment process are related to later depression, especially when the child is raised in an abusive environment (Toth & Cicchetti, 1996), and to later conduct disorder (Sampson & Laub, 1993). The relationship of attachment to mental disorders has been the subject of several important review articles (Rutter, 1995; van IJzendoorn et al., 1995).

There is controversy as to whether the key determinant of "insecure" responses to strange situations stems from maternal behavior or from an inborn predisposition to respond to an unfamiliar stranger with avoidant behaviors, such as is found in socially phobic children (Belsky & Rovine, 1987; Kagan et al., 1988; Thompson et al., 1988; Kagan, 1994, 1995). Kagan demonstrated that infants who were more prone to being active, agitated, and tearful at 4 months of age were less spontaneous and sociable and more likely to show anxiety symptoms at age 4 (Snidman et al., 1995; Kagan et al., 1998). These findings are of considerable significance, because long-term study of such highly reactive, behaviorally inhibited infants and toddlers has shown that they are excessively shy and avoidant in early childhood and that this behavior persists and predisposes to later anxiety (Biederman et al., 1993). There is also some controversy as to whether "difficult" temperament in an infant is an early manifestation of a behavior problem, particularly in children who go on to demonstrate such problems as conduct disorder (Olds et al., 1999). One analysis of the attachment literature suggests that abnormal or insecure forms of attachment are largely the *product* of maternal problems, such as depression and substance abuse, rather than of individual differences in the child (van IJzendoorn et al., 1992).

The relationship between a child's temperament and parenting style is complex (Thomas et al., 1968); it may be either protective if it is good or a risk factor if it is poor. Thus, a difficult child's chances of developing mental health problems are much reduced if he or she grows up in a family in which there are clear rules and consistent enforcement (Maziade et al., 1985), while a child exposed to inconsistent discipline is at greater risk for later behavior problems (Werner & Smith, 1992).

Family and Genetic Risk Factors

As noted above in the relationships between temperament and attachment, in some instances the relative contributions of biologic influences and environmental influences are difficult to tease apart, a problem that particularly affects studies investigating the impact of family and genetic influences on risk for childhood mental disorder. For example, research has shown that between 20 and 50 percent of depressed children and adolescents have a family history of depression (Puig-Antich et al., 1989; Todd et al., 1993; Williamson et al., 1995; Kovacs, 1997b). The exact reasons for this increased risk have not been fully clarified, but experts tend to agree that both factors interact to result in this increased risk (Weissman et al., 1997). Family research has found that children of depressed parents are more than three times as likely as children of nondepressed parents to experience a depressive disorder (see Birmaher et al., 1996a and 1996b for review). Parental depression also increases the risk of anxiety disorders, conduct disorder, and alcohol dependence (Downey & Coyne, 1990; Weissman et al., 1997; Wickramaratne & Weissman, 1998). The risk is greater if both parents have had a depressive illness, if the parents were depressed when they were young, or if a parent had several episodes of depression (Merikangas et al., 1988; Downey & Coyne, 1990; McCracken, 1992a, 1992b; Mufson et al., 1992; Warner et al., 1995; Wickramaratne & Weissman, 1998).

Effects of Parental Depression

Depressed parents may be withdrawn and lack energy and consequently pay little attention to, or provide inadequate supervision of, their children. Alternatively, such parents may be excessively irritable and overcritical, thereby upsetting children, demoralizing them, and distancing them (Cohn et al., 1986; Field et al., 1990). At a more subtle level, parents' distress—being pessimistic, tearful, or threatening suicide—is sometimes seen or heard by the child, thereby inducing anxiety. Depressed parents may not model effective coping strategies for stress; instead of "moving on," some provide an example of "giving up" (Garber & Hilsman, 1992). Depression is also often associated with marital discord, which may have its own adverse effect on children and adolescents. Conversely, the behavior of the depressed child or teenager may contribute to family stress as much as being a product of it. The poor academic performance, withdrawal from normal peer activities, and lack of energy or motivation of a depressed teenager may lead to intrusive or reprimanding reactions from parents that may further reduce the youngster's self-esteem and optimism.

The consequences of maternal depression vary with the state of development of the child, and some of the effects are quite subtle (Cicchetti & Toth, 1998). For example, in infancy, a withdrawn or unresponsive depressed mother may increase an infant's distress, and an intrusive or hostile depressed mother may lead the infant to avoid looking at and communicating with her (Cohn et al., 1986). Other studies have shown that if infants' smiles are met with a somber or gloomy face, they respond by showing a similarly somber expression and then by averting their eyes (Murray et al., 1993).

During the toddler stage of development, research shows that the playful interactions of a toddler with a depressed mother are often briefer and more likely to be interrupted (by either the mother or the child) than those with a nondepressed parent (Jameson et al., 1997). Research has shown that some depressed mothers are less able to provide structure or to modify the behavior of excited toddlers, increasing the risk of out-of-control behavior, the development of a later conduct disorder, or later aggressive dealings with peers (Zahn-Waxler et al., 1990; Hay et al., 1992). A depressed mother's inability to control a young child's behavior may result in the child failing to learn appropriate skills for settling disputes without reliance on aggression.

Stressful Life Events

The relationship between stressful life events and risk for child mental disorders is well established (e.g., Garmezy, 1983; Hammen, 1988; Jensen et al., 1991; Garber & Hilsman, 1992), although this relationship in children and adolescents is complicated, perhaps reflecting the impact of individual differences and developmental changes. For example, there is a relationship between stressful life events, such as parental death or divorce, and the onset of major depression in young children, especially if they occur in early childhood and lead to a permanent and negative change in the child's circumstances. Yet findings are mixed as to whether the same relationship is true for depression in midchildhood or in adolescence (Birmaher et al., 1996a and 1996b; Garrison et al., 1997).

Childhood Maltreatment

Child abuse is a very widespread problem; it is estimated that over 3 million children are maltreated every year in the United States (National Committee to Prevent Child Abuse, 1995). Physical abuse is associated with insecure attachment (Main & Solomon, 1990), psychiatric disorders such as post-traumatic stress disorder, conduct disorder, ADHD (Famularo et al., 1992), depression (Kaufman, 1991), and impaired social functioning with peers (Salzinger et al., 1993). Psychological maltreatment is believed to occur more frequently than physical maltreatment (Cicchetti & Carlson, 1989); it is associated with depression, conduct disorder, and delinquency (Kazdin et al., 1985) and can impair social and cognitive functioning in children (Smetana & Kelly, 1989).

Peer and Sibling Influences

The influence of maladaptive peers can be very damaging to a child and greatly increases the likelihood of adverse outcomes such as delinquency, particularly if the child comes from a family beset by many stressors (Friday & Hage, 1976; Loeber & Farrington, 1998). One way to reduce antisocial behavior in adolescents is to encourage such youths to interact with better adapted youths under the supervision of a mental health worker (Feldman et al., 1983). Sibling rivalry is a common component of family life and, especially in the presence of other risk factors, may contribute to family stresses (Patterson & Dishion, 1988). Although almost universal, in the presence of other risk factors it may be the origin of aggressive behavior that eventually extends beyond the family (Patterson & Dishion, 1988). In stressed or large families, parents have many demands placed on their time and find it difficult to oversee, or place limits on, their young children's behavior. When parental attention is in short supply, young siblings squabbling with each other attract available attention. In such situations, parents rarely comment on good or neutral behavior but do pay attention, even if in a highly critical and negative way, when their children start to fight; as a result, the act of fighting may be inadvertently rewarded. Thus, any attention, whether it be praise or physical punishment, increases the likelihood that the behavior is repeated.

Correlations and Interactions Among Risk Factors

Recent evidence suggests that social/environmental risk factors may combine with physical risk factors of the child, such as neurological damage caused by birth complications or low birth-weight, fearlessness and stimulation-seeking behavior, learning impairments, autonomic underarousal, and insensitivity to physical pain and punishment (Raine et al., 1996, 1997, 1998). However, testing models of the impact of risk factor interactions for the development of mental disorders is difficult, because some of the risk factors are difficult to measure. Thus, the trend these days is to move away from the consideration of *individual* risk factors toward identifying *measurable* risk factors and their *combinations* and incorporating all of them into a single model that can be tested (Patterson, 1996).

The next section describes a series of preventive interventions directed against the environmental risk factors described above.

Prevention

Childhood is an important time to prevent mental disorders and to promote healthy development, because many adult mental disorders have related antecedent problems in childhood. Thus, it is logical to try to intervene early in children's lives before problems are established and become more refractory. The field of prevention has now developed to the point that reduction of risk, prevention of onset, and early intervention are realistic possibilities. Scientific methodologies in prevention are increasingly sophisticated, and the results from high-quality research trials are as credible as those in other areas of biomedical and psychosocial science. There is a growing recognition that prevention does work; for example, improving parenting skills through training can substantially reduce antisocial behavior in children (Patterson et al., 1993).

The wider human services and law enforcement communities, not just the mental health community, have made prevention a priority. Policymakers and service providers in health, education, social services, and juvenile justice have become invested in intervening early in children's lives: they have come to appreciate that mental health is inexorably linked with general health, child care, and success in the classroom and inversely related to involvement in the juvenile justice system. It is also perceived that investment in prevention may be cost-effective. Although much research still needs to be done, communities and managed health care organizations eager to develop, maintain, and measure empirically supported preventive interventions are encouraged to use a risk and evidence-based framework developed by the National Mental Health Association (Mrazek, 1998).

Some forms of primary prevention are so familiar that they are no longer thought of as mental health prevention activities, when, in fact, they are. For example, vaccination against measles prevents its neurobehavioral complications; safe sex practices and maternal screening prevent newborn infections such as syphilis and HIV, which also have neurobehavioral manifestations. Efforts to control alcohol use during pregnancy help prevent fetal alcohol syndrome (Stratton et al., 1996). All these conditions may produce mental disorders in children.

This section describes several exemplary interventions that focus on enhancing mental health and primary prevention of behavior problems and mental health disorders. Prevention of a disorder or its recurrence or exacerbation is discussed together with that disorder in other sections of this chapter. Prevention strategies usually target high-risk infants, young children, adolescents, and/or their caregivers, addressing the risk factors described above.

Project Head Start

Project Head Start, though generally conceived of as an early childhood intervention program, is probably this country's best known prevention program. In 1965, when it was designed and first implemented in 2,500 communities, Head Start's target population was economically disadvantaged preschool children. Its goal was to improve the social competence of these children through an 8-week comprehensive intervention that included a center-based component and a home visit by community aides, focusing on social, health, and education services (Karoly et al., 1998). A number of psychologists, most notably Jerome Bruner (1971), argued that children can be *trained* to think in a more logical way and that the development of logic is not entirely predetermined. Bruner's views were very influential in launching early intervention programs such as Head Start. There is now ample evidence that, by providing an appropriately stimulating environment, significant advances in knowledge and reasoning ability can be achieved.

The program has served over 15 million children and has cost $31 billion since its inception (General Accounting Office, 1997). It has changed in many ways in the intervening years, and there now is considerable program variation across localities (Zigler & Styfco, 1993). Early evaluations of Head Start showed promising results in terms of higher IQ scores, but over the years many of the findings have met with criticism and skepticism. The reason is that there has been no national randomized controlled trial to evaluate the program as originally designed (Karoly et al., 1998).

Repeated evaluations of Head Start programs that did not employ such a rigorous design (Berrento-Clement et al., 1984; Seitz et al., 1985; Lee et al., 1990; Yoshikawa, 1995) have shown that, although focused early education can improve test scores, the advantage is short-lived. The test scores of children of comparable ability who do not receive early childhood education quickly catch up with those who have been in Head Start programs (Lee et al., 1990). Yet there appear to be more enduring academic outcomes. A review of 36 studies of Head Start and other early childhood programs found them to lower enrollment in special education and to enhance rates of high school graduation and promotion to the next grade level (Barnett, 1995). Head Start and other forms of early education offer arguably even more important benefits, which do not become apparent until children are older. The advantages are mainly social, rather than cognitive, and include better peer relations, less truancy, and less antisocial behavior (Berrento-Clement et al., 1984; Provence, 1985; Seitz et al., 1985; Webster-Stratton, 1998; Weikart, 1998). Although important from a societal perspective, it is not known whether these very significant benefits are due to direct effects on the child or to the parent education programs that often accompany Head Start programs (Zigler & Styfco, 1993).

Carolina Abecedarian Project

The Carolina Abecedarian Project is an example of an early educational intervention for high-risk children that has been tested more rigorously than Head Start in well-designed, randomized, and controlled trials. It addresses the issue of the timing of the intervention, that is, when an intervention should begin and how long it should continue. Unlike Head Start, children were enrolled in this program at birth and remained in it for several years.

In the Carolina Abecedarian Project, children who had been identified at birth as being at high risk for school failure on the basis of social and economic variables were enrolled in a child-centered prevention-oriented intervention program delivered in a day care setting from infancy to age 5 (Campbell & Ramey, 1994[1]). The preschool intervention operated 8 hours a day for 50 weeks a year and included an infant curriculum to enhance development and parent activities. At elementary school age, a second intervention was provided: the children, who were then in kindergarten, received 15 home visits a year for 3 years from a teacher who prepared a home program to supplement the school's basic curriculum. There were significant positive effects from the two-phase intervention on intellectual development and academic achievement, and these effects were maintained through age 12, which was 4 years after the intervention ended.

Infant Health and Development Program

The Infant Health and Development Program (IHDP) also began at birth and continued for several years and was also designed for low-birth-weight and premature infants (McCarton et al., 1997[2]). The intervention was provided until the children reached 3 years of age. It included pediatric care, home visits, parent group meetings, and center-based schooling 5 days a week from 12 months of age to 3 years. At the end of the intervention, the group receiving it had significantly higher mean IQ scores than did the control group. Of note, although children's behavior problems were not targeted by the intervention, mothers of children in the intervention group reported significantly fewer behavior problems than those in the control group.

Elmira Prenatal/Early Infancy Project

The Elmira Prenatal/Early Infancy Project is an excellent example of a preventive intervention that targeted an at-risk population to prevent the onset of a series of health, social, and mental health problems in children and in their mothers (Olds et al., 1998 and previous years[3]). This study warrants special attention because of its positive and enduring findings, randomized, controlled design, cost-benefit analysis, and unusually long-term follow up of 15 years. The study began by focusing on pregnant women bearing their first child in a small, semirural county in upstate New York. The children of these women were considered high risk because of their mother's young maternal age, single-parent status, or low socioeconomic level. There were four study groups to which random assignment was made. The first group received developmental screening at ages 1 and 2; the second group received screening and free transportation to health care; the third group received screening, transportation, and nurse home visits once every 2 weeks during pregnancy; and the fourth group received all of the above plus continued home visits by a nurse on a diminishing schedule until the infants were 24 months of age. The intervention focused on parent education, enhancement of the women's informal support systems, and linkage with community services.

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[1] Also see Ramey et al., 1984; Ramey & Campbell, 1984; Horacek et al., 1987; Martin et al., 1990.

[2] Also see IHDP, 1990; Ramey et al., 1992; Brooks-Gunn et al., 1994a, 1994b; Casey et al., 1994.

[3] Also see Olds et al., 1986a, 1986b, 1988, 1993, 1994a, 1994b, 1995, and 1997.

Women in both groups receiving home visits from nurses had many positive behavioral outcomes compared with groups that received screening only or screening plus transportation. Among the women at highest risk for caregiver dysfunction, those who were visited by a nurse had fewer instances of verified child abuse and neglect during the first 2 years of their children's lives. They were observed in their homes to restrict and punish their children less frequently, and they provided more appropriate play materials. There were no differences between groups in the rates of new cases of child abuse and neglect or in the children's intellectual functioning in the period when the children were 25 to 48 months of age. However, nurse-visited children had fewer behavioral and parental coping problems (as noted in the physician record). Nurse-visited mothers were observed to be more involved with their children than were mothers in the comparison groups.

A cost-benefit analysis estimated program costs (direct costs of nurse visitation, costs of services to which nurses linked families, and costs of transportation) and benefits (cost outcomes presumed to be affected by the program through improved maternal and child functioning, such as less use of Aid to Families With Dependent Children, Medicaid, food stamps, child protective services, and greater tax revenues generated by women's working). Taking a time point of 2 years after the program ended, the net cost of the program for the sample as a whole was $1,582 per family, but for low-income families, the cost of the program was recovered with a dividend of $180 per family.

Fifteen years after the birth of the index child (13 years after termination of the intervention), women who were visited by nurses during pregnancy and infancy had significantly fewer subsequent pregnancies, less use of welfare, fewer verified reports of abuse and neglect, fewer behavioral impairments due to use of alcohol and other drugs, and fewer arrests. Their children, now adolescents, reported fewer instances of running away, fewer arrests, fewer convictions and violations of probation, fewer lifetime sex partners, fewer cigarettes smoked per day, and fewer days having consumed alcohol in the last 6 months. The parents of these adolescents reported that their children had fewer behavioral problems related to use of alcohol and other drugs.

Primary Mental Health Project

The Primary Mental Health Project (PMHP) is a 42-year-old program for early detection and prevention of young children's school adjustment problems. PMHP currently operates in approximately 2,000 schools in 700 school districts nationally and internationally. Seven states in the United States are implementing the program systematically, based on authorizing legislation and state appropriations.

PMHP has four key elements: (1) a focus on primary grade children; (2) systematic use of brief objective screening measures for early identification of children in need; (3) use of carefully selected, trained, closely supervised nonprofessionals (called child associates) to establish a caring and trusting relationship with children; and (4) a changing role for the school professionals that features selection, training, and supervision of child associates, early systematic screening, and functioning as program coordinator, liaison, and consultant to parents, teachers and other school personnel.

The PMHP model has been applied flexibly to diverse ethnic and sociodemographic groups in settings where help is most needed. Over 30 program evaluation studies, including several at the state level, underscore the program's efficacy (Cowen et al., 1996). Significant improvements were detected in children's grades, achievement test scores, and adjustment ratings by teachers and child associates. PMHP represents a successful mental health intervention that does not require highly trained and skilled mental health professionals.

Other Prevention Programs and Strategies

These and other prevention trials demonstrate that positive adaptation and social-emotional well-being in children and youth can be enhanced, and that risk factors for behavioral and emotional disorders can be reduced, by intervening in home, school, day care, and other settings. Programs have focused not only on mental health problems but also on other problem behaviors (Botvin et al., 1995; St. Lawrence et al., 1995; Kellam & Anthony, 1998).

Other prevention trials are showing similar benefits. For example, a large-scale, four-site school- and home-based prevention trial, known as FastTrack, has shown clear benefits in reducing behavior problems among high-risk children, as well as in reducing needs for and use of special education, which has substantial cost-effectiveness implications (Conduct Problems Prevention Research Group, 1999a, 1999b). Another trial is now under way to test the efficacy of a preventive intervention provided to adolescents whose parents are currently being treated for depression within a health maintenance organization (Clark et al., 1998). Treatment of mood disorders also has potential effectiveness for the primary prevention of suicide, as explained in the later section on Depression and Suicide in Children and Adolescents.

Overview of Mental Disorders in Children

A consideration of developmental principles enhances understanding of mental illness in children and adolescents by reconciling the concept of mental disorder as a stable state or condition with the ongoing development of the child. According to these principles, a mental disorder results from the interaction of a child and his or her environment. Thus, mental illness often does not lie within the child alone. Within the conceptual framework and language of integrative neuroscience, the mental disorder is an "emergent property" of the transaction with the environment. Proper assessment of a child's mood, thought, and behaviors demands a simultaneous consideration of nature and nurture, genes and environment, and biology and psychosocial influences. These relationships are reciprocal. The brain shapes behavior, and learning shapes the brain.

Mental disorders must be considered within the context of the family and peers, school, home, and community. Taking the social-cultural environment into consideration is essential to understanding mental disorders in children and adolescents, as it is in adults. However, the changing nature of these environments, coupled with the progressively unfolding processes of brain development, makes the emphasis on context, as well as development, more complex *and* more central in child mental health (Jensen & Hoagwood, 1997).

Thus, developmental psychopathology encourages consideration of the transactions between the individual and the social and physical environment at the same time that signs and symptoms of mental disorder are considered. Moreover, focusing on diagnostic labels alone provides too limited a view of mental disorders in children and adolescents.

General Categories of Mental Disorders of Children

Mental disorders with onset in childhood and adolescence are listed in Table 3-2 as they appear in DSM-IV. These disorders fall into a number of broad categories, most of which apply not just to children but across the entire life span: anxiety disorders; attention-deficit and disruptive behavior disorders; autism and other pervasive developmental disorders; eating disorders (e.g., anorexia nervosa); elimination disorders

Table 3-2. Selected mental disorders of childhood and adolescence from the DSM-IV

- Anxiety Disorders
- Attention-Deficit and Disruptive Behavior Disorders
- Autism and Other Pervasive Developmental Disorders
- Eating Disorders
- Elimination Disorders
- Learning and Communication Disorders
- Mood Disorders (e.g., Depressive Disorders)
- Schizophrenia
- Tic Disorders

(e.g., enuresis, encopresis); learning and communication disorders; mood disorders (e.g., major depressive disorder, bipolar disorder); schizophrenia; and tic disorders (Tourette's disorder). Several of the more common childhood conditions are described below.

Disorders of anxiety and mood are characterized by the repeated experience of intense internal or emotional distress over a period of months or years. Feelings associated with these conditions may be those of unreasonable fear and anxiety, lasting depression, low self-esteem, or worthlessness. Syndromes of depression and anxiety very commonly co-occur in children. The disorders in this broad group include separation anxiety disorder, generalized anxiety disorder, post-traumatic stress disorder, obsessive-compulsive disorder, major depressive disorder, dysthymia, and bipolar disorder (DSM-IV).

Children who suffer from attention-deficit disorder, disruptive disorder, and oppositional defiant disorder may be inattentive, hyperactive, aggressive, and/or defiant; they may repeatedly defy the societal rules of the child's own cultural group or disrupt a well-ordered environment such as a school classroom.

Children with autism and other pervasive developmental disorders often suffer from disordered cognition or thinking and have difficulty understanding and using language, understanding the feelings of others, or, more generally, understanding the world around them. Such disorders are often associated with severe learning difficulties and impaired intelligence. The disorders in this category include the pervasive developmental disorders, autism, Asperger's disorder, and Rett's disorder (DSM-IV).

It is not uncommon for a child to have more than one disorder or to have disorders from more than one of these groups. Thus, children with pervasive developmental disorders often suffer from ADHD. Children with a conduct disorder are often depressed, and the various anxiety disorders may co-occur with mood disorders. Learning disorders are common in all these conditions, as are alcohol and other substance use disorders (DSM-IV).

Assessment and Diagnosis

As with adults, assessment of the mental function of children has several important goals: to learn the unique functional characteristics of each individual (sometimes called formulation) and to diagnose signs and symptoms that suggest the presence of a mental disorder. Case formulation helps the clinician understand the child in the context of family and community. Diagnosis helps identify children who may have a mental disorder with an expected pattern of distress and limitation, course, and recovery. Both processes are useful in planning for treatment and supportive care. Both are helpful in developing a treatment plan.

Even with the aid of widely used diagnostic classification systems such as DSM-IV (see Chapter 2), diagnosis and diagnostic classification present a greater challenge with children than with adults for several reasons. Children are often unable to verbalize thoughts and feelings. Clinicians by necessity become more reliant on parents, teachers, and other professionals, who may be unable to assess these mental processes in children. Children's normal development also presents an ever-changing backdrop that complicates clinical presentation. As previously noted, some behaviors may be quite normal at one age but suggest mental illness at another age. Finally, the criteria for diagnosing most mental disorders in children are derived from those for adults, even though relatively little research attention has been paid to the validity of these criteria in children. Expression, manifestation, and course of a disorder in children might be very different from those in adults. The boundaries between normal and abnormal are less distinct and those between one diagnosis and another are fluid.

Thus, the field of childhood mental health historically downplayed diagnosis. This trend began to change in the 1980s, in part as a result of developing practice guidelines and tougher reimbursement standards (Lonigan et al., 1998) and more appropriate diagnostic categories and criteria (DSM III, III-R, and IV). The body of accumulated research on treatment and services referred to throughout this chapter reflects the past emphasis on the efficacy of treatments, sometimes with and sometimes independently of diagnosis.

Most disorders are diagnosed by their manifestations, that is, by symptoms and signs, as well as functional impairment (see Chapter 2). A diagnosis is made when the combination and intensity of symptoms and signs meet the criteria for a disorder listed in DSM-IV. However, diagnosis of childhood mental disorders, as noted earlier, is rarely an easy task. Many of the symptoms, such as outbursts of aggression, difficulty in paying attention, fearfulness or shyness, difficulties in understanding language, food fads, or distress of a child when habitual behaviors are interfered with, are normal in young children and may occur sporadically throughout childhood. Well-trained clinicians overcome this problem by determining whether a given symptom is occurring with an unexpected frequency, lasting for an unexpected length of time, or is occurring at an unexpected point in development. Clinicians with less experience may either overdiagnose normal behavior as a disorder or miss a diagnosis by failing to recognize abnormal behavior. Inaccurate diagnoses are more likely in children with mild forms of a disorder.

Evaluation Process

When conducted by a mental health professional, the evaluation process usually consists of gathering information from several sources: the child, parents, teachers, pediatricians, and hospital records. The mental health professional also makes observations of the child's or teenager's behavior and patterns of speech. Very often, additional testing is requested to assess the child's or youth's intelligence and learning abilities. Information about symptoms can be obtained more reliably by direct questioning (Gittelman-Klein, 1978; Gittelman, 1985).

A full evaluation may take several hours. By that time, the professional should have a good understanding of how the child is functioning at home, at school, and in society and some understanding of the family's characteristics. With this information, the child or adolescent psychiatrist, clinical psychologist, or social worker can suggest further investigations and, if needed, initiate treatment of the child and provide counseling to parents and teachers on how to best assist the child or teenager to overcome problems.

There is a dearth of child psychiatrists, appropriately trained clinical child psychologists, or social workers (Thomas & Holzer, 1999). Furthermore, many barriers remain that prevent children, teenagers, and their parents from seeking help from the small number of specially trained professionals who are available. This places a burden on pediatricians, family physicians, and other gatekeepers (such as school counselors and primary child care workers) to identify children for referral and treatment decisions. These gatekeepers are unlikely to have the time and specialized training to do an evaluation requiring several hours. Their responsibility often is to "triage" cases, that is, refer children who need further evaluation to specialists. Many, however, are involved in treating children and adolescents. They may be greatly aided by various diagnostic aids such as brief questionnaires that can be completed in the waiting room of the pediatrician, the school counseling office, or some other community setting. Ideally, these screening questionnaires would be accompanied by a clear guide on interpreting results and identifying what kind of score or behavior would normally indicate a need for referral to a professional.

Some of the questionnaires that specifically address mood disorders are shown in Figure 3-1. Other questionnaires, such as the Adolescent Antisocial Self-Report Behavior Checklist (Kulik et al., 1968), the Eyberg Child Behavior Inventory (Eyberg & Robinson, 1983), and the Family Interaction Coding Pattern (Patterson, 1982), assess antisocial behavior. Adults and teachers can use instruments such as the Child Behavior Checklist (Achenbach & Edelbrock, 1983) to assess a relatively full range of behavioral and emotional symptoms and disorders from the perspective of adult informants. The Minnesota Multiphasic Personality Inventory-2 (MMPI-2; Hathaway & McKinley, 1989) and the Millon Adolescent Personality Inventory (MAPI) (Millon et al., 1982) questionnaires may be used with adolescents to assess normal and abnormal personality function.

Figure 3-1. Questionnaires used to assess childhood mood disorders

Title	Source
The Children's Depression Inventory (CDI)	Kovacs, 1985
Beck Depression Inventory (BDI)	Beck, Ward, Mendelson, Mock, & Erbaugh, 1961
Reynolds Adolescent Depression Scale (RADS)	Reynolds, 1986
Children's Depression Scale (CDS)	Tisher & Lang, 1983
Center for Epidemiological Studies of Depression (CES-D)	Radloff, 1977
Kandel Depression Scale (KDS)	Kandel & Davies, 1982
Zung Self-Rating Depression Scale (SDS)	Zung, 1965
Diagnostic Interview Schedule for Children (DISC)	Shaffer & Fisher, 1998

The advent of highly structured, computer-driven assessment tools, such as the NIMH Diagnostic Interview Schedule for Children, which comes in a spoken version that can be given through headphones to children and/or their parents (Shaffer et al., 1996a), promises to greatly improve the ability of professionals outside of the mental health field to obtain robust diagnostic information, which can guide them in decisions about further referral or treatment.

Treatment Strategies

Children and adolescents receive most of the traditional treatments described in Chapter 2, particularly psychosocial treatments, such as psychotherapies, and various medications. Specific psychosocial and pharmacological treatment approaches are described in subsequent sections on specific mental disorders. Much of the research, however, has been conducted on adults, with results extrapolated to children. Some of the treatments, such as interactive or play therapy with young children, are unique to clinical work with this group, while others, such as individual psychotherapy with adolescents, are similar to clinical work with adults. Many of the treatment interventions have been "packaged" together in particular arrangements for delivery in specific clinical settings.

More attention is being paid to the value of multimodal therapies, that is, the combination of pharmacological and psychosocial therapies. While research is limited, multimodal studies have shown benefits for treatment of ADHD (see later section), anxiety (Kearney & Silverman, 1998), and depression. Tempering the value of psychotherapy as well as pharmacotherapy, which is discussed below, is that the efficacy of these therapies in the research setting is greater than that in the real world. The problem of the gap between research and clinical practice is discussed in greater depth elsewhere in this chapter and in Chapter 2.

Psychotherapy

The major types of psychotherapy for children are supportive, psychodynamic, cognitive-behavioral, interpersonal, and family systemic. With the exception of the latter, these therapies originally were developed for adults and then tailored for use in children.

Most psychotherapies are deemed effective for children and adolescents because they improve more than with no treatment, as discussed later in this chapter under Treatment Interventions (Casey & Berman, 1985; Hazelrigg et al., 1987; Weisz et al., 1987; Kazdin et al., 1990; Baer & Nietzel, 1991; Grossman & Hughes, 1992; Shadish et al., 1993; Weisz & Weiss, 1993; Weisz et al., 1995). But despite this strong body of research on children comparing treatment with no treatment, far less attention has been paid to, and guidance provided about, the efficacy of a given psychotherapy for a specific diagnosis (Lonigan et al., 1998). In other words, it is not clear which therapies are best for which conditions. The American Psychological Association sought to rectify this problem by convening two task forces, the second of which exhaustively reviewed the professional literature to evaluate the strength of the evidence for treating individual disorders in children. The second task force refined two sets of criteria against which to evaluate the evidence: the first, and more rigorous, set of criteria was for *Well-Established Psychosocial Interventions*, while the other was for *Probably Efficacious Psychosocial Interventions* (Lonigan et al., 1998). The findings of the task force's comprehensive evaluation were published, disorder by disorder, in an entire issue of the *Journal of Clinical Child Psychology* in June 1998. While findings relating to individual disorders are presented in the next section of this chapter, this was the overarching conclusion: ". . . the majority of these [psychosocial] interventions do not meet criteria for the highest level of empirical support, the well-established criteria" (Lonigan et al., 1998). The problem, according to these authors, is that too few well-controlled studies have been performed for each disorder. To meet the criteria for a *Well-Established Psychosocial Intervention*, there must be at least two well-conducted group-design studies conducted by different teams of researchers, among other criteria.[4] Hereafter, these criteria are referred to as the American Psychological Association Task Force Criteria.

Some other general points are warranted about the value of psychotherapies for children. Psychotherapies are especially important alternatives for those children who are unable to tolerate, or whose parents prefer them not to take, medications. They also are important for conditions for which there are no medications with well-documented efficacy. They also are pivotal for families under stress from a child's mental disorder. Therapies can serve to reduce stress in parents and siblings and teach parents strategies for managing symptoms of the mental disorder in their child (see later sections on Disruptive Disorders and Home-Based Services).

Psychopharmacology

Dramatic increases have occurred over the past decade in the use of pharmacological therapies for children and adolescents with mental disorders, but research has lagged behind the surge in their use (Jensen et al., 1999). Our gaps in knowledge span three areas in particular. First, for most prescribed medications, there are no studies of safety and efficacy for children and adolescents. This is true for medications for mental disorders as well as for somatic disorders. Depending on the specific medication, evidence may be lacking for short-term, or most commonly, for long-term safety and efficacy. The problem is even more pronounced with newer medications, most of which have been introduced into the market for adults. Only in the case of psychostimulants for ADHD is there an adequate body of research on their safety and efficacy in children and adolescents, albeit short-term information only (Greenhill et al., 1998) (see later section on ADHD). Second, there is often limited information about pharmacokinetics, that is, drug concentrations in body fluids and tissues over time (Clein & Riddle, 1996). Most of what is known about pharmacokinetics comes from studies of adults. But pediatric pharmacokinetic studies are crucial to identifying the appropriate dose and dose frequency for children of different ages and body sizes. Third, the combined effectiveness of pharmacological and psychosocial treatments, that is, multimodal treatments, is seldom studied. Multimodal treatments have the potential to yield dose reductions in pharmacological treatments, thereby improving the side-effect profile, parental acceptance, and patient compliance.

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[4] The criteria are listed in Chapter 1.

The dearth of research on children and adolescents has allowed for widespread "off-label" use of medications. This means that, for this population, physicians who are prescribing a given drug do not have the benefit of research and drug labeling information developed by the sponsor and approved by the Food and Drug Administration (FDA). Under U.S. food and drug law, a drug is approved by the FDA only for a defined population. Yet after its approval and market availability, physicians are at liberty to prescribe it for anyone, even though the sponsor only is allowed to *market* the drug for the approved population (which typically is adults) (FDA, 1998). Fortunately, there is a large body of clinical experience with children and adolescents to guide prescribing practices, despite few controlled studies (Green, 1996).

There are several reasons for the paucity of research on medications for children and adolescents. One is greater caution on the part of both the medical profession and parents to experiment with children or to prescribe drugs with potentially serious side effects. Another reason is the need for compliance with dosing requirements of the clinical trial protocol. When children are research subjects, enforcing compliance is generally perceived to be more difficult. Researchers must rely on parents to assess the degree of compliance. A final reason is the cost of research. Once drugs have reached the market for adults, pharmaceutical companies have fewer financial incentives to conduct expensive and methodologically demanding studies with children, to whom drugs may be given through off-label prescribing. The problem has been significant enough to have galvanized Congress into passing legislation, the FDA Modernization Act of 1997, to create financial incentives for drug sponsors to conduct research with pediatric subjects [FDA, 1999 Title 21 USC 505A(g)]. The FDA Modernization Act may help alleviate this problem, but it is too early to tell.

Despite the relative lack of information concerning safety and efficacy of psychotropic agents in children, six scientific reviews have been completed recently; these reviews comprehensively surveyed all available published research concerning the safety and efficacy of psychotropic medication, focusing on six general classes of medication: the psychostimulants (Greenhill et al., 1998), the mood stabilizers and antimanic agents (Ryan et al., 1999), the selective serotonin reuptake inhibitors (SSRIs) (Emslie et al., 1999), antidepressants (Geller et al., 1998), antipsychotic agents (Campbell et al., 1999), and other miscellaneous agents (Riddle et al., 1998).

Review of this comprehensive body of research evidence indicates strong support for the safety and efficacy of several classes of agents for several conditions, specifically, SSRIs for childhood/adolescent obsessive-compulsive disorder, and the psychostimulants for ADHD. For many other disorders and medications, however, information from rigorously controlled trials is sparse or altogether absent (see Figure 3-2). Further, only in the area of ADHD is information now emerging on longer term safety and efficacy, as well as on the merits of combining psychopharmacologic and psychotherapeutic treatments.

Given the inadequacy of efficacy data for most nonstimulant psychotropics, studies are needed for the majority of agents. However, efficacy data appear to be most urgently needed for SSRIs, mood stabilizers, and novel antipsychotics, since the level of usage of these medications appears to be highest among the growing list of psychotropic medications used in youth (Fisher & Fisher, 1996). In contrast to adult psychopharmacology that is focusing on differential efficacy and speed of onset of these categories of psychotropics,

Figure 3-2. Grading the Level of Evidence for Efficacy of Psychotropic Drugs in Children

Category	Indication	Level of Supporting Data				Estimated Frequency of Use
		Short-Term Efficacy	Long-Term Efficacy	Short-Term Safety	Long-Term Safety	Rank
Stimulants	ADHD	A	B	A	A	1
Selective Serotonin Reuptake Inhibitors	Major depression	B	C	A	C	2
	OCD	A	C	A	C	
	Anxiety disorders	C	C	C	C	
Central Adrenergic Agonists	Tourette syndrome	B	C	B	C	3
	ADHD	C	C	C	C	
Valproate and Carbamazepine	Bipolar disorders	C	C	A	A	4
	Aggressive conduct	C	C	A	A	
Tricyclic Antidepressants	Major depression	C	C	B	B	5
	ADHD	B	C	B	B	
Benzodiazepines	Anxiety disorders	C	C	C	C	6
Antipsychotics	Childhood schizophrenia and psychoses	B	C	C	B	7
	Tourette syndrome	A	C	B	B	
Lithium	Bipolar disorders	B	C	B	C	8
	Aggressive conduct	B	C	C	C	

Key: A = $\geq$ 2 randomized controlled trials (RCTs).
B = At least 1 RCT.
C = Clinical opinion, case reports, and uncontrolled trials.

Source: Jensen et al., 1999

pediatric psychopharmacology needs basic studies of efficacy.

Additional information on specific medication treatment is presented in the succeeding sections, providing more detailed discussion of particular disorders. Indepth information is presented on two disorders where a great deal of research has been done, namely, ADHD and major depressive disorder, followed by briefer discussions of other childhood mental disorders.

Attention-Deficit/Hyperactivity Disorder

As its name implies, attention-deficit/hyperactivity disorder (ADHD) is characterized by two distinct sets of symptoms: inattention and hyperactivity-impulsivity (see Table 3-3). Although these problems usually occur together, one may be present without the other to qualify for a diagnosis (DSM-IV). Inattention or attention deficit may not become apparent until a child enters the challenging environment of elementary school. Such children then have difficulty paying attention to details and are easily distracted by other events that are occurring at the same time; they find it difficult and unpleasant to finish their schoolwork; they put off anything that requires a sustained mental effort; they are prone to make careless mistakes, and are disorganized, losing their school books and assignments; they appear not to listen when spoken to and often fail to follow through on tasks (DSM-IV; Waslick & Greenhill, 1997).

Table 3-3. DSM-IV criteria for Attention-Deficit/Hyperactivity Disorder

A. Either (1) or (2):

(1) six (or more) of the following symptoms of **inattention** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:
Inattention

(a) often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities
(b) often has difficulty sustaining attention in tasks or play activities
(c) often does not seem to listen when spoken to directly
(d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions)
(e) often has difficulty organizing tasks and activities
(f) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)
(g) often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books, or tools)
(h) is often easily distracted by extraneous stimuli
(i) is often forgetful in daily activities

(2) six (or more) of the following symptoms of **hyperactivity-impulsivity** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity

(a) often fidgets with hands or feet or squirms in seat
(b) often leaves seat in classroom or in other situations in which remaining seated is expected
(c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
(d) often has difficulty playing or engaging in leisure activities quietly
(e) is often "on the go" or often acts as if "driven by a motor"
(f) often talks excessively

Impulsivity

(g) often blurts out answers before questions have been completed
(h) often has difficulty awaiting turn
(i) often interrupts or intrudes on others (e.g., butts into conversations or games)

B. Some hyperactive-impulsive or inattentive symptoms that cause impairment were present before age 7 years.

C. Some impairment from the symptoms is present in two or more settings (e.g., at school [or work] and at home).

D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of a pervasive developmental disorder, schizophrenia, or other psychotic disorder and are not better accounted for by another mental disorder (e.g., mood disorder, anxiety disorder, dissociative disorder, or a personality disorder).

The symptoms of hyperactivity may be apparent in very young preschoolers and are nearly always present before the age of 7 (Halperin et al., 1993; Waslick & Greenhill, 1997). Such symptoms include fidgeting, squirming around when seated, and having to get up frequently to walk or run around. Hyperactive children have difficulty playing quietly, and they may talk excessively. They often behave in an inappropriate and uninhibited way, blurting out answers in class before the teacher's question has been completed, not waiting their turn, and interrupting often or intruding on others' conversations or games (Waslick & Greenhill, 1997).

Many of these symptoms occur from time to time in normal children. However, in children with ADHD they occur very frequently and in several settings, at home and at school, or when visiting with friends, and they interfere with the child's functioning. Children suffering from ADHD may perform poorly at school; they may be unpopular with their peers, if other children perceive them as being unusual or a nuisance; and their behavior can present significant challenges for parents, leading some to be overly harsh (DSM-IV).

Inattention tends to persist through childhood and adolescence into adulthood, while the symptoms of motor hyperactivity and impulsivity tend to diminish with age. Many children with ADHD develop learning difficulties that may not improve with treatment (Mannuzza et al., 1993). Hyperactive behavior is often associated with the development of other disruptive disorders, particularly conduct and oppositional-defiant disorder (see Disruptive Disorders). The reason for the relationship is not known. Some believe that the impulsivity and heedlessness associated with ADHD interfere with social learning or with close social bonds with parents in a way that predisposes to the development of behavior disorders (Barkley, 1998).

Even though a great many children with this disorder ultimately adjust (Mannuzza et al., 1998), some—especially those with an associated conduct or oppositional-defiant disorder—are more likely to drop out of school and fare more poorly in their later careers than children without ADHD. As they grow older, some teens who have had severe ADHD since middle childhood experience periods of anxiety or depression. This seems to be especially common in children whose predominant symptom is inattention (Morgan et al., 1996). Excellent reviews of ADHD can be found in DSM-IV and other sources.[5]

Prevalence

ADHD, which is the most commonly diagnosed behavioral disorder of childhood, occurs in 3 to 5 percent of school-age children in a 6-month period (Anderson et al., 1987; Bird et al., 1988; Esser et al., 1990; Pelham et al., 1992; Shaffer et al., 1996c; Wolraich et al., 1996). Pediatricians report that approximately 4 percent of their patients have ADHD (Wolraich et al., 1990), but in practice the diagnosis is often made in children who meet some, but not all, of the criteria recommended in DSM-IV (Wolraich et al., 1990) (see also Treatment later in this section). Boys are four times more likely to have the illness than girls are (Ross & Ross, 1982). The disorder is found in all cultures, although prevalences differ; differences are thought to stem more from differences in diagnostic criteria than from differences in presentation (DSM-IV).

Causes

The exact etiology of ADHD is unknown, although neurotransmitter deficits, genetics, and perinatal complications have been implicated. In the early post-World War II years, a number of pediatricians, neurologists, and child psychiatrists noted that brain-damaged children were often hyperactive (Strauss & Lehtinen, 1947; Eisenberg, 1957; Laufer & Denhoff, 1957). These observations led to the diagnostic concept of "minimal brain damage" (Wender, 1971), which was thought to be characterized by hyperactivity, inattention, learning difficulties, and a wide variety of behavior problems. However, large epidemiological studies (Rutter & Quinton, 1977) of grossly brain-damaged children with cerebral palsy, epilepsy, and so forth, did not find an excess of hyperactivity, and more recent imaging studies have found no evidence of gross brain damage in children with ADHD (Swanson et al., 1998). The past view that ADHD is a form of minimal brain damage has therefore been abandoned by experts. Many brain-damaged children are, if anything, significantly underactive.

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[5] Taylor, 1994; Cantwell, 1996; Waslick & Greenhill, 1997, Barkley, 1998; and NIH Consensus Statement 110, 1998

In the late 1970s, it was postulated that the core problem in hyperkinetic children was one of inattention (Douglas & Peters, 1979). This view led, in 1980, to the adoption, in the official DSM-III (American Psychiatric Association, 1980) nomenclature, of the new diagnostic label *attention-deficit disorder*.

Because the symptoms of ADHD respond well to treatment with stimulants, and because stimulants increase the availability of the neurotransmitter dopamine, the "dopamine hypothesis" has gained a wide following. The dopamine hypothesis posits that ADHD is due to inadequate availability of dopamine in the central nervous system. The neurotransmitter dopamine plays a key role in initiating purposive movement, increasing motivation and alertness, reducing appetite, and inducing insomnia, effects that are often seen when a child responds well to methylphenidate. The dopamine hypothesis has thus driven much of the recent research into the causes of ADHD.

The fact that ADHD runs in families suggests that inheritance is an important risk factor. Between 10 and 35 percent of children with ADHD have a first-degree relative with past or present ADHD. Approximately one-half of parents who had ADHD have a child with the disorder (Biederman et al., 1995). Over the past decade, a large number of twin studies have shown that, when ADHD is present in one twin, it is significantly more likely also to be present in an identical twin than in a fraternal twin (Goodman & Stevenson, 1989). These findings have led geneticists to estimate that genes are important in a high proportion of children with ADHD.

Research to pinpoint abnormal genes is honing in on two genes: a dopamine-receptor (DRD) gene on chromosome 11 and the dopamine-transporter gene (DAT1) on chromosome 5 (Cook et al., 1995; Smalley et al., 1998). Several studies have found evidence that children with ADHD have genetic variations in one of the dopamine-receptor genes (DRD4), although the largest of these studies suggests that the presence of such a variation is associated with only a modest increase in the risk of developing ADHD (Smalley et al., 1998). Several other studies have found evidence for abnormalities of the dopamine-transporter gene (DAT1) in children with very severe forms of ADHD (Cook et al., 1995; Gill et al., 1997; Waldman et al., 1998).

Yet for most children with ADHD, the overall effects of these gene abnormalities appear small, suggesting that nongenetic factors also are important. Although none of the many imaging studies have found evidence of gross brain damage, some investigators have suggested that exposure to toxins, such as lead, or episodes of oxygen deprivation for the fetus, as may occur during some complications of pregnancy, may adversely affect dopamine-rich areas of the brain. These theories support observations that hyperactivity and inattention are more common in children whose mothers smoked during pregnancy (Nichols & Chen, 1981), in children who have been exposed to high quantities of lead (Needleman et al., 1990), and in children who had a lack of oxygen in the neonatal period (Whittaker et al., 1997).

Some investigators have noted that the parents of hyperactive children are often overintrusive and overcontrolling (Carlson et al., 1995). It has therefore been suggested that such parental behavior is another possible risk factor for ADHD. However, others have noted that, when children are treated with methylphenidate, there is a reduction in parental negativity and intrusiveness. This suggests that the observed overintrusive and overcontrolling behavior of the parent is a response to the child's behavior rather than the cause (Barkley et al., 1985).

Treatment

The American Academy of Child and Adolescent Psychiatry (AACAP) published "practice parameters" (i.e., guidelines for clinical practice) on the diagnosis and treatment of ADHD. The AACAP parameters include an extensive literature review, detailed descriptions of the clinical presentation of the disorder, and recommendations for treatment. The practice parameters state that "the cornerstones of treatment are support and education of parents, appropriate school placement, and pharmacology" (AACAP, 1991). These practice parameters evolved out of research relating to two major types of treatment: pharmacological treatment and psychosocial treatment, particularly behavioral modification, as well as multimodal treatment, the combination of psychosocial and pharmacological treatments.

Pharmacological Treatment

Psychostimulants

Pharmacological treatment with psychostimulants is the most widely studied treatment for ADHD. Stimulant treatment has been used for childhood behavioral disorders since the 1930s (Bradley, 1937). Psychostimulants are highly effective for 75 to 90 percent of children with ADHD. At least four separate psychostimulant medications consistently reduce the core features of ADHD in literally hundreds of randomized controlled trials: methylphenidate, dextroamphetamine, pemoline, and a mixture of amphetamine salts (Spencer et al., 1995; Greenhill, 1998a, 1998b; Greenhill et al., 1998).

These medications are metabolized, leave the body fairly quickly, and work for 1 to 4 hours. Administration is timed to meet the child's school schedule, to help the child pay attention and meet his or her academic demands, and to mitigate side effects. These medications have their greatest effects on symptoms of hyperactivity, impulsivity, and inattention and the associated features of defiance, aggression, and oppositionality. They also improve classroom performance and behavior and promote increased interaction with teachers, parents, and peers. Small effects were found on learning and school achievement (see reviews by Barkley, 1990; Pelham, 1993; Swanson et al.,1993, 1995b; Greenhill et al., 1998; Cantwell, 1996a; Spencer et al., 1996.) However, psychostimulants do not appear to achieve long-term changes in outcomes such as peer relationships, social or academic skills, or school achievement (Pelham et al., 1998).

Children who do not respond to one stimulant may respond to another (Elia et al., 1991; Elia & Rapoport, 1991). Children should be reevaluated without the medication to see if stimulant treatment is still indicated. Many families choose to have their child take a "drug holiday" on weekends and vacations to reduce overall exposure, but the utility of this strategy has not been demonstrated (AACAP, 1991).

Dosing

Stimulants are usually started at a low dose and adjusted weekly (AACAP, 1991). A recent study demonstrated that the practice of dosing methylphenidate on the basis of body weight fails to predict the optimal dose of medication (Rapport & Denney, 1997). One of the goals of the recently completed NIMH Multimodal Treatment Study of ADHD (described more fully below) was to develop medication strategies to guide "best dose," dose changes, management of side effects, and integration with other treatments (Greenhill et al., 1996).

Side Effects

Common stimulant side effects include insomnia, decreased appetite, stomach aches, headaches, and jitteriness. Some children may develop tics, but a recent study suggests that they disappear with continued treatment (Gadow et al., 1995). Rebound activation (i.e., a sudden increase in attention deficit and hyperactivity) has been noted anecdotally after the child's last dose of medication wears off (Johnston et al., 1988). Most of the side effects are mild, recede over time, and respond to dose changes. Children rarely experience cognitive impairment, which, if it does occur, can be resolved with reduction or cessation of the drug (Cantwell, 1996). A few cases of psychosis have been reported. Pemoline has been associated with hepatotoxicity, so monitoring of liver function is necessary. Two studies have shown no long-term effects of stimulants on later height or weight (Klein & Mannuzza, 1988; Vincent et al., 1990). Nonetheless, regular precautionary monitoring of weight and height for children on stimulants is recommended.

Other Medications

For children with ADHD who do not respond to stimulants (10 to 30 percent) or cannot tolerate the side effects, there are other useful medications. The antidepressant bupropion has been found to be superior to placebo, although the response is not as strong as that found with stimulants (Cantwell, 1998). Bupropion can also be used as an adjunct to augment stimulant treatment. Well-controlled trials have shown tricyclic antidepressants to be superior to placebo but less effective than stimulants (Elia et al., 1991; Elia & Rapoport, 1991). Reports of sudden death of a few children in the early 1990s on the tricyclic compound desipramine led to great caution with the use of tricyclics in children (Riddle et al., 1991).

Considerable controversy surrounds the use of central alpha-adrenergic blocking drugs, such as clonidine and guanfacine, to treat ADHD. There is some evidence that clonidine is effective for ADHD when it occurs with a tic disorder (Hunt, 1987; Hunt et al., 1990, 1995). Caution is warranted in view of the four cases of sudden death that have been reported in children taking methylphenidate and clonidine together and of a number of reports of nonfatal cardiac side effects in children taking clonidine alone or in combination (Swanson et al., 1995a).

Neuroleptics have been found to be occasionally effective (Green, 1995), yet the risk of movements disorders, such as tardive dyskinesia, makes their use problematic. Lithium, fenfluramine, or benzodiazapines have not been found to be effective treatments for ADHD (Cantwell, 1996a; Green, 1995), nor have SSRIs, such as fluoxetine (Goldman et al., 1998). Furthermore, more than 20 studies have shown that dietary manipulation (e.g., the Feingold diet) is not efficacious (Mattes & Gittelman, 1981), and controlled studies failed to demonstrate that sugar exacerbates the symptoms of children with ADHD (Milich & Pelham, 1986).

Psychosocial Treatment

Important options for the management of ADHD are psychosocial treatments, particularly in the form of training in behavioral techniques for parents and teachers. Behavioral techniques, which are described more fully below, typically employ "time-out," point systems and contingent attention (adults reinforcing appropriate behavior by paying attention to it). Psychosocial treatments are useful for the child who does not respond to medication at all or for whom the therapeutic benefits of the medication have worn off and for the child who responds only partially to medication or cannot tolerate medication. In addition, some families express a strong preference not to use medication. Even children who are receiving medication may continue to have residual ADHD symptoms or symptoms from other disorders, such as oppositional defiant disorder or depression, which make specialized child management skills necessary and helpful (see next section, Multimodal Treatments). Furthermore, children with ADHD can present a challenge that puts significant stress on the family. Skills training for parents can help reduce this stress on parents and siblings.

Behavioral Approaches

The main psychosocial treatments for ADHD are behavioral training for parent and teacher, as well as systematic programs of contingency management (this behavioral technique is described in more detail in the Treatment section later in this chapter). Of these options, systematic programs of intensive contingency management conducted in specialized classrooms or summer camps with the setting controlled by highly trained individuals is the most effective (Abramowitz et al., 1992; Carlson et al., 1992; Pelham & Hoza, 1996). The efficacy of behavioral training of teachers is *well-established*, while the evidence for parent training is less solid, according to the criteria, noted earlier, promulgated by the American Psychological

Association Task Force (Pelham et al., 1998). There is, however, indirect support for the effectiveness of parent training in the literature, demonstrating the efficacy of parent training for children with oppositional defiant disorder who share many characteristics with children who have ADHD (see section on Disruptive Disorders).

A number of studies have compared parent training (Gittelman et al., 1980; Firestone et al., 1986; Horn et al., 1987, 1990, 1991; Pelham et al., 1988) or school-based behavioral modification (Gittelman et al., 1980; Pelham et al., 1988) with the use of stimulants. Most of the studies are of outpatient behavioral therapy programs in which parents meet in groups and are taught behavioral techniques such as time out, point systems, and contingent attention. Teachers are taught similar classroom strategies, as well as the use of a daily report card for parents that evaluates the child's in-school behavior. The improvements in the symptoms of ADHD achieved with psychosocial treatments are not as large as those found with psychostimulants (Pelham et al., 1998). Behavioral interventions tend to improve targeted behaviors or skills but are not as helpful in reducing the core symptoms of inattention, hyperactivity, or impulsivity. Questions remain about the effectiveness of these treatments in other settings. To be fully effective, treatments for ADHD need to be conducted across settings (school, home, community) and by different people (e.g., parents, teachers, therapists)—a consistency and comprehensiveness that can be hard to achieve.

Cognitive-Behavioral Therapy

Cognitive-behavioral therapy (CBT), primarily training in problem solving and social skills, has not been shown to provide clinically important changes in behavior and academic performance of children with ADHD (Pelham et al., 1998). However, CBT might be helpful in treating symptoms of accompanying disorders such as oppositional defiant disorder, depression, or anxiety disorders (Abikoff, 1985; Hinshaw & Ehardt, 1991; Lochman, 1992).

Psychoeducation

Although there are no studies evaluating the efficacy of psychoeducation as a treatment modality for ADHD, providing information to parents, children, and teachers about ADHD and treatment options is considered critical in the development of a comprehensive treatment plan (AACAP, 1991). Educational accommodations for children with ADHD are federally mandated, and mental health providers are required to ensure that patients and families have access to adequate and appropriate educational resources. Organizations such as Children and Adults with Attention Deficit Disorder (CHADD) and the National Attention Deficit Disorder Association can be helpful sources of information and support for families.

Multimodal Treatments

Many researchers and families have long suspected that multimodal treatment—medication used together with multiple psychosocial interventions in multiple settings—should be more effective than medication alone. Multimodal treatment has thus been used in the absence of empirical support (Hechtman, 1993). To determine whether multimodal treatment is indeed effective, the recent NIMH Multimodal Treatment Study of ADHD (called the MTA Study) examined three experimental conditions: medication management alone, behavioral treatment alone, or a combination of medication and behavioral treatments. The study compared the effectiveness of these three treatment modes with each other and with standard care provided in the community (the control group). The behavioral treatment condition consisted of parent training, a school intervention, and a summer treatment program. The MTA Study was also designed to determine the relative benefits of these treatments over time (Richters et al., 1995). All subjects were treated for 14 months and then followed for an additional 22 months.

Results of the MTA Study comparing the 14-month outcomes of 579 children randomly assigned to one of the four treatment conditions were presented in the fall of 1998 (MTA Cooperative Group, 1998). At 14 months, medication and the combination treatment were generally more effective than the behavioral treatment alone or the control treatment. Notably, the combined treatment resulted in significant improvement over the control condition in six outcome areas—social skills, parent child relations, internalizing (e.g., anxiety) symptoms, reading achievement, oppositional and/or aggressive symptoms, and parent and/or consumer satisfaction—whereas the single forms of treatment (medication *or* behavior therapy) were each superior to the control condition in only one to two of these domains. The conclusions from this major study are that carefully managed and monitored stimulant medication, alone or combined with behavioral treatment, is effective for ADHD over a period of 14 months. Addition of behavioral treatment yields no additional benefits for core ADHD symptoms but appears to provide some additional benefits for non-ADHD-symptom outcomes.

Treatment Controversies

Overprescription of Stimulants

Concerns have been raised that children, particularly active boys, are being overdiagnosed with ADHD and thus are receiving psychostimulants unnecessarily. However, recent reports found little evidence of overdiagnosis of ADHD or overprescription of stimulant medications (Goldman et al., 1998; Jensen et al., 1999). Indeed, fewer children (2 to 3 percent of school-aged children) are being treated for ADHD than suffer from it. Treatment rates are much lower for selected groups such as girls, minorities, and children receiving care though public service systems (Bussing et al., 1998a, 1998b). However, there have been major increases in the number of stimulant prescriptions since 1989 (Hoagwood et al., 1998), and methylphenidate is being manufactured at 2.5 times the rate of a decade ago (Goldman et al., 1998). Most researchers believe that much of the increased use of stimulants reflects better diagnosis and more effective treatment of a prevalent disorder. Medical and public awareness of the problem of ADHD has grown considerably, leading to longer treatment, fewer interruptions in treatment, and increased treatment of adults. Adolescents and younger girls with ADHD, who were underdiagnosed in the past, are being identified and treated.

Nonetheless, some of the increase in use may reflect inappropriate diagnosis and treatment. In one study, the rate of stimulant treatment was twice the rate of parent-reported ADHD, based on a standardized psychiatric interview (Angold & Costello, 1998). While many children who do meet the full criteria for ADHD are not being treated, the majority of children and adolescents who are receiving stimulants did not fully meet the criteria. These findings may reflect a failure of proper, comprehensive evaluation and diagnosis rather than a failure of the diagnostic criteria, which are clear and validated by research (Angold & Costello, 1998). A diagnosis of ADHD requires the presence of impairing ADHD symptoms in *multiple* settings for at least 6 months. Although fidgeting and not paying attention are normal, common childhood behaviors, DSM-IV criteria reserve a diagnosis of ADHD for children in whom such frequent behavior produces persistent and pervasive dysfunction. An adequate diagnostic evaluation requires histories to be taken from multiple sources (parents, child, teachers), a medical evaluation of general and neurological health, a full cognitive assessment including school history, use of parent and teacher rating scales, and all necessary adjunct evaluation (such as assessment of speech, language). These evaluations take time and require multiple clinical skills. Regrettably, there is a dearth of appropriately trained professionals.

Family practitioners are more likely than either pediatricians or psychiatrists to prescribe stimulants and less likely to use diagnostic services, provide mental health counseling, or provide followup care (Hoagwood et al., 1998). The American Academy of Pediatrics published a policy statement in 1996 on the use of medication for children with attentional disorders, concluding that use of medication should not be considered the complete treatment program for children with ADHD and should be prescribed only after a careful evaluation (American Academy of Pediatrics Committee on Children With Disabilities and Committee on Drugs, 1996).

Safety of Long-Term Stimulant Use

Even though the MTA Study found no safety issues over a 14-month period (Greenhill et al., 1998), concerns have been raised about the longer term safety of stimulant treatment. Since ADHD has an early onset and requires an extended course of treatment, research is needed to examine the long-term safety of treatment and to investigate whether other forms of treatment could be combined with psychostimulants to lower their dose as well as to reduce other problem behaviors found with ADHD. Such combined treatments could be targeted for symptoms of disorders that often accompany ADHD, such as conduct disorder, substance abuse, and learning disabilities, and could be targeted to improve overall functioning (Laufer, 1971; Gittelman et al., 1985).

Because stimulants are also drugs of abuse and because children with ADHD are at increased risk for a substance abuse disorder, concerns have also been raised about the potential for abuse of stimulants by children taking the medication or diversion of the drug to others. While stimulants clearly have abuse potential, the rate of lifetime nonmedical methylphenidate use has not significantly increased since methylphenidate was introduced as a treatment for ADHD, suggesting that abuse is not a major problem (Goldman et al., 1998). Case reports describing abuse by children prescribed stimulants for ADHD are rare (Hechtman, 1985).

Depression and Suicide in Children and Adolescents

In children and adolescents, the most frequently diagnosed mood disorders are major depressive disorder, dysthymic disorder, and bipolar disorder. Because mood disorders such as depression substantially increase the risk of suicide, suicidal behavior is a matter of serious concern for clinicians who deal with the mental health problems of children and adolescents. The incidence of suicide attempts reaches a peak during the midadolescent years, and mortality from suicide, which increases steadily through the teens, is the third leading cause of death at that age (CDC, 1999; Hoyert et al., 1999). Although suicide cannot be defined as a mental disorder, the various risk factors—especially the presence of mood disorders—that predispose young people to such behavior are given special emphasis in this section, as is a discussion of the effectiveness of various forms of treatment. The evidence is strong that over 90 percent of children and adolescents who commit suicide have a mental disorder, as explained later in this section.

Major depressive disorder is a serious condition characterized by one or more major depressive episodes. In children and adolescents, an episode lasts on average from 7 to 9 months (Birmaher et al., 1996a, 1996b) and has many clinical features similar to those in adults. Depressed children are sad, they lose interest in activities that used to please them, and they criticize themselves and feel that others criticize them. They feel unloved, pessimistic, or even hopeless about the future; they think that life is not worth living, and thoughts of suicide may be present. Depressed children and adolescents are often irritable, and their irritability may lead to aggressive behavior. They are indecisive, have problems concentrating, and may lack energy or motivation; they may neglect their appearance and hygiene; and their normal sleep patterns are disturbed (DSM-IV).

Despite some similarities, childhood depression differs in important ways from adult depression. Psychotic features do not occur as often in depressed children and adolescents, and when they occur, auditory hallucinations are more common than delusions (Ryan et al., 1987; Birmaher et al., 1996a, 1996b). Associated anxiety symptoms, such as fears of separation or reluctance to meet people, and somatic symptoms, such as general aches and pains, stomachaches, and headaches, are more common in depressed children and adolescents than in adults with depression (Kolvin et al., 1991; Birmaher et al., 1996a, 1996b).

Dysthymic disorder is a mood disorder like major depressive disorder, but it has fewer symptoms and is more chronic. Because of its persistent nature, the disorder is especially likely to interfere with normal adjustment. The onset of dysthymic disorder (also called dysthymia) is usually in childhood or adolescence (Akiskal, 1983; Klein et al., 1997). The child or adolescent is depressed for most of the day, on most days, and symptoms continue for several years. The average duration of a dysthymic period in children and adolescents is about 4 years (Kovacs et al., 1997a). Sometimes children are depressed for so long that they do not recognize their mood as out of the ordinary and thus may not complain of feeling depressed. Seventy percent of children and adolescents with dysthymia eventually experience an episode of major depression[6] (Kovacs et al., 1994). When a combination of major depression and dysthymia occurs, the condition is referred to as *double depression*.

Bipolar disorder is a mood disorder in which episodes of mania alternate with episodes of depression. Frequently, the condition begins in adolescence. The first manifestation of bipolar illness is usually a depressive episode. The first manic features may not occur for months or even years thereafter, or may occur either during the first depressive illness or later, after a symptom-free period (Strober et al., 1995).

The clinical problems of mania are very different from those of depression. Adolescents with mania or hypomania feel energetic, confident, and special; they usually have difficulty sleeping but do not tire; and they talk a great deal, often speaking very rapidly or loudly. They may complain that their thoughts are racing. They may do schoolwork quickly and creatively but in a disorganized, chaotic fashion. When manic, adolescents may have exaggerated or even delusional ideas about their capabilities and importance, may become overconfident, and may be "fresh" and uninhibited with others; they start numerous projects that they do not finish and may engage in reckless or risky behavior, such as fast driving or unsafe sex. Sexual preoccupations are increased and may be associated with promiscuous behavior.

Reactive depression, also known as adjustment disorder with depressed mood, is the most common form of mood problem in children and adolescents. In children suffering from reactive depression, depressed feelings are short-lived and usually occur in response to some adverse experience, such as a rejection, a slight, a letdown, or a loss. In contrast, children may feel sad or lethargic and appear preoccupied for periods as short as a few hours or as long as 2 weeks. However, mood improves with a change in activity or an interesting or pleasant event. These transient mood swings in reaction to minor environmental adversities are not regarded as a form of mental disorder.

Conditions Associated With Depression

Roughly two-thirds of children and adolescents with major depressive disorder also have another mental disorder (Angold & Costello, 1993; Anderson & McGee, 1994). The most commonly associated disorders are dysthymia (see above), an anxiety disorder, a disruptive or antisocial disorder, or a substance abuse disorder. When more than one diagnosis is present, depression is more likely to begin after the onset of the accompanying disorder, except when that disorder is substance abuse (Biederman et al., 1995; Kessler & Walters, 1998). This suggests that, in some cases, depression may arise in response to the associated disorder. In other instances, such as the co-occurrence of conduct disorder and depression, the two may arise independently in response to inadequate maternal supervision and control, raising the possibility that parental behavior may be a risk factor for both conditions (Downey & Coyne, 1990; Rutter & Sandberg, 1992; Harrington, 1994).

Prevalence

Major Depression

Population studies show that at any one time between 10 and 15 percent of the child and adolescent population has *some* symptoms of depression (Smucker et al., 1986). The prevalence of the full-fledged diagnosis of major depression among all children ages 9 to 17 has been estimated at 5 percent (Shaffer et al., 1996c). Estimates of 1-year prevalence in children range from 0.4 and 2.5 percent and in adolescents, considerably higher (in some studies, as high as 8.3

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[6] Major depression refers to conditions marked by a major depressive episode, such as major depressive disorder, bipolar disorder, and related conditions. The word "major" refers to the number of symptoms. See Chapter 4 for DSM-IV diagnostic criteria.

percent) (Anderson & McGee, 1994; Lewinsohn et al., 1994a; Garrison et al., 1997; Kessler & Walters, 1998). For purposes of comparison, 1-year prevalence in adults is about 5.3 percent (Murphy et al., 1988; Rorsman et al., 1990; Regier et al., 1993).

Dysthymic Disorder

The prevalence of dysthymic disorder in adolescents has been estimated at around 3 percent (Garrison et al., 1997). Before puberty, major depressive disorder and dysthymic disorder are equally common in boys and girls (Rutter, 1986). But after age 15, depression is twice as common in girls and women as in boys and men (Weissman & Klerman, 1977; McGee et al., 1990; Linehan et al., 1993).

Suicide

In 1996, the age-specific mortality rate from suicide was 1.6 per 100,000 for 10- to 14-year-olds, 9.5 per 100,000 for 15- to 19-year-olds (i.e., about six times higher than in the younger age group; in this age group, boys are about four times as likely to commit suicide than are girls, while girls are twice as likely to attempt suicide), compared with 13.6 per 100,000 for 20- to 24-year-olds (CDC, 1999). Hispanic high school students are more likely than other students to attempt suicide (CDC, 1998). There have been some notable changes in these rates over the past few decades: since the early 1960s, the reported suicide rate among 15- to 19-year-old males increased threefold but remained stable among females in that age group and among 10- to 14-year-olds (National Center for Health Statistics, 1998); the rate among white adolescent males reached a peak in the late 1980s (18.0 per 100,000 in 1986) and has since declined somewhat (16.0 per 100,000 in 1997), whereas among African American male adolescents, the rate increased substantially in the same period (from 7.1 per 100,000 in 1986 to 11.4 per 100,000 in 1997 (CDC, 1998). From 1979 to 1992, the Native American male adolescent and young adult suicide rate in Indian Health Service Areas was the highest in the Nation, with a suicide rate of 62.0 per 100,000 (Wallace et al., 1996).

It has been proposed that the rise in suicidal behavior among teenage boys results from increased availability of firearms (Boyd, 1983; Boyd & Moscicki, 1986; Brent et al., 1987; Brent et al., 1991) and increased substance abuse in the youth population (Shaffer et al., 1996c; Birckmayer & Hemenway, 1999). However, although the rate of suicide by firearms increased more than suicide by other methods (Boyd, 1983; Boyd & Moscicki, 1986; Brent et al., 1987), suicide rates also increased markedly in many other countries in Europe, in Australia, and in New Zealand, where suicide by firearms is rare.

Course and Natural History

Most children with depression experience a recurrence. Twenty to 40 percent of depressed children relapse within 2 years, and 70 percent will do so by adulthood (Garber et al., 1988; Velez et al., 1989; Harrington et al., 1990; Fleming et al., 1993; Kovacs et al., 1994; Lewinsohn et al., 1994a; Garrison et al., 1997). The reasons for relapse are not known, but there is some evidence that experiencing a depression leaves behind psychological "scars" that may increase vulnerability throughout early life (see below).

The age of first onset of depression appears to play a role in its course. Children who first become depressed before puberty are at risk for some form of mental disorder in adulthood, while teenagers who first become depressed after puberty are most likely to experience another episode of depression (Harrington et al., 1990; McCracken, 1992a; Lewinsohn et al., 1994a, 1994b; Rao et al., 1995). These differences in outcome suggest that different mechanisms may lead to superficially similar but inherently different clinical conditions. Factors that worsen the prognosis for depressed children and adolescents include depression occurring in the context of conduct disorder (Harrington et al., 1990; Asarnow et al., 1994) and living in conflict-ridden families (Asarnow et al., 1994). Children and particularly adolescents who suffer from depression are at much greater risk of committing suicide than are children without depression (Shaffer et al., 1996b).

The prognosis for dysthymia (Klein et al., 1997a) is unfavorable, with most patients continuing to feel depressed and to have social difficulties even after they have apparently recovered. The prognosis for double depressives (major depressive disorder plus dysthymia) is worse than that for either condition alone (Kovacs et al., 1994).

Twenty to 40 percent of adolescents with depression eventually develop bipolar disorder. Factors that predict later bipolar disorder include young age at the time of the first depressive episode, psychotic features in the initial depression, a family history of bipolar illness, and symptoms of hypomania developing during treatment with antidepressant drugs (Garber et al., 1988; Strober et al., 1993).

Causes

The precise causes of depression are not known. Extensive research on adults with depression generally points to both biological and psychosocial factors (Kendler, 1995). However, there has been substantially less research on the causes of depression in children and adolescents. Further discussion of the risk factors for depression can be found in Chapter 4, as well as the preceding Overview of Risk Factors and Prevention section.

Family and Genetic Factors

Much of the research on children and adolescents with depression has been conducted with those who attend mental health clinics and with patients who tend to have the more severe and recurrent forms of depression, and thus they may not be representative of all children and adolescents with depression. With this limitation, research has shown that between 20 and 50 percent of depressed children and adolescents have a family history of depression (Puig-Antich et al., 1989; Todd et al., 1993; Williamson et al., 1995; Kovacs, 1997b). Family research has found that children of depressed parents are more than three times as likely as children with nondepressed parents to experience a depressive disorder (see Birmaher et al., 1996a, 1996b for a review). They also are more vulnerable to other mental and somatic disorders (Downey & Coyne, 1990). Conversely, estimates of the proportion of depressed parents who have a depressed child or adolescent vary from approximately one in six to just under a half (Hammen et al., 1990). It is not clear whether the relationship between parent and childhood depression derives from genetic factors, or whether depressed parents create an environment that increases the likelihood of a mental disorder developing in their children (see below).

Gender Differences

One reason advanced to explain the greater prevalence of depression in adolescent girls (see above) is that they are more socially oriented, more dependent on positive social relationships, and more vulnerable to losses of social relationships than are boys (Allgood-Merten et al., 1990). This would increase their vulnerability to the interpersonal stresses that are common in teenagers. There is also evidence that the methods girls use to cope with stress may entail less denial and more focused and repetitive thinking about the event (Nolen-Hoeksema & Girgus, 1994). The higher prevalence, therefore, could be a result of greater vulnerability, combined with coping mechanisms different than those of boys.

Biological Factors

Some of the core symptoms of depression, such as changes in appetite and sleep patterns, are related to the functions of the hypothalamus. The hypothalamus is, in turn, closely tied to the function of the pituitary gland. Abnormalities of pituitary function, such as increased rates of circulating cortisol and hypo- or hyperthyroidism, are well established features of depression in adults (Goodwin & Jamison, 1990). However, far less research has been done in this area among children and adolescents (see Birmaher et al., 1996a, 1996b for a review). It is in the neuroendocrine area that most research has been done on child and adolescent depression (see Birmaher et al., 1996a, b). In suicidal adults dysregulation of the serotonergic system is common (Mann, 1998; Pine et al., 1995), making them typically impulsive, intense, and given to extreme reactions. However, little is known about the association between abnormal serotonin metabolism and suicidal behavior in children and adolescents.

Cognitive Factors

For over two decades there has been considerable interest in the relationship between a particular "mindset" or approach to perceiving external events and a predisposition to depression. The mindset in question is known as a pessimistic "attribution bias" (Abramson et al., 1978; Beck, 1987; Hops et al., 1990). A person with this mindset is one who readily assumes personal blame for negative events ("All the problems in the family are my fault"), who expects that one negative experience is part of a pattern of many other negative events ("Everything I do is wrong"), and who believes that a currently negative situation will endure permanently ("Nothing I do is going to make anything better"). Such pessimistic individuals take a characteristically negative view of positive events (i.e., that they are a result of someone else's effort, that they are isolated events, and that they are unlikely to recur). Individuals with this mindset react more passively, helplessly, and ineffectively to negative events than those without a pessimistic mindset (Seligman, 1975).

There is uncertainty over whether this mindset precedes depression (and represents a permanent style of thinking as part of an individual's personality), is a manifestation of depression that is only present when the patient is depressed, and/or is a consequence or "scar" of a previous, perhaps unnoticed, depressive episode (Lewinsohn et al., 1981). This pessimistic mode of thinking does not occur in children under age 5, which could be one of the reasons why depression and suicide are rare in early childhood (Rholes et al., 1980; Rotenberg, 1982).

There is evidence that children and adolescents who previously have been depressed may learn, during their depression, to interpret events in this fashion. This may make them prone to react similarly to negative events experienced after recovery, which could be one of the reasons why previously depressed children and adolescents are at continuing risk for depression (Nolen-Hoeksema et al., 1993).

Perceptions of hopelessness, negative views about one's own competence, poor self- esteem, a sense of responsibility for negative events, and the immutability of these distorted attributions may contribute to the hopelessness that has been repeatedly found to be associated with suicidality (Overholser et al., 1995).

Risk Factors for Suicide and Suicidal Behavior

There is good evidence that over 90 percent of children and adolescents who commit suicide have a mental disorder before their death (Shaffer & Craft, 1999). The most common disorders that predispose to suicide are some form of mood disorder, with or without alcoholism or other substance abuse problem, and/or certain forms of anxiety disorder (Shaffer et al., 1996b). Psychological postmortem studies also show that a significant proportion of suicide victims suffered from an anxiety disorder at the time of their death, but the number of victims has been too small to yield precise odds ratios for the calculation of an effect. Although the rate of suicide is greatly increased in schizophrenia, because of its rarity, it accounts for very few suicides in the child and adolescent age group.

Controlled studies of completed suicide suggest similar risk factors for boys and girls (Shafii et al., 1985; Brent et al., 1988; Groholt et al., 1997), but with marked differences in their relative importance (Shaffer et al., 1996c).

Among girls, the most significant risk factor is the presence of major depression, which, in some studies, increases the risk of suicide 12-fold. The next most important risk factor is a previous suicide attempt, which increases the risk approximately threefold. Among boys, a previous suicide attempt is the most potent predictor, increasing the rate over 30-fold. It is followed by depression (increasing the rate by about 12-fold), disruptive behavior (increasing the rate by twofold), and substance abuse (increasing the rate by just under twofold) (Shaffer et al., 1996c).

Stressful life events often precede a suicide and/or suicide attempt (de Wilde et al., 1992; Gould et al., 1996). As indicated earlier, these stressful life events include getting into trouble at school or with a law enforcement agency; a ruptured relationship with a boyfriend or a girlfriend; or a fight among friends.[7] They are rarely a sufficient cause of suicide, but they can be precipitating factors in young people.

Controlled studies (Gould et al., 1996; Hollis, 1996) indicate that low levels of communication between parents and children may act as a significant risk factor. While family discord, lack of family warmth, and disturbed parent-child relationship are commonly associated with child and adolescent psychopathology (violent behavior, mood disorder, alcohol and substance abuse disorders) (Brent et al., 1994; Pfeffer et al., 1994), these factors do not play a specific role in suicide (Gould et al., 1998).

Evidence has accumulated that supports the observation that suicide can be facilitated in vulnerable teens by exposure to real or fictional accounts of suicide (Velting & Gould, 1997), including media coverage of suicide, such as intensive reporting of the suicide of a celebrity, or the fictional representation of a suicide in a popular movie or TV show. The risk is especially high in the young, and it lasts for several weeks (Gould & Shaffer, 1986; Phillips et al., 1989). The suicide of a prominent person reported on television or in the newspaper or exposure to some sympathetic fictional representation of suicide may also tip the balance and make the at-risk individual feel that suicide is a reasonable, acceptable, and in some instances even heroic, decision (Gould & Shaffer, 1986).

The phenomenon of suicide clusters is presumed to be related to imitation (Davidson, 1989). Suicide clusters nearly always involve previously disturbed young people who knew about each other's death but rarely knew the other victims personally (Gould, personal communication, 1999).

Consequences

Both major depressive disorder and dysthymic disorder are inevitably associated with personal distress, and if they last a long time or occur repeatedly, they can lead to a circumscribed life with fewer friends and sources of support, more stress, and missed educational and job opportunities (Klein et al., 1997). The psychological scars of depression include an enduring pessimistic style of interpreting events, which may increase the risk of further depressive episodes. Impairment is greater for those with dysthymic disorder than for those with major depression (Klein et al., 1997a), presumably because of the longer duration of depression in dysthymic disorder, which is also a prime risk factor for suicide. In a 10- to 15-year followup study of 73 adolescents diagnosed with major depression, 7 percent of the adolescents had committed suicide sometime later. The depressed adolescents were five times more likely to have attempted suicide as well, compared with a control group of age peers without depression (Weissman et al., 1999).

Treatment

Depression

Psychosocial Interventions

To be deemed effective and approved by the American Psychological Association, treatments for mental disorders have to meet very strict criteria. While interpersonal therapy and systemic family therapy show promise, they have not been studied sufficiently to evaluate their effectiveness by these standards. However, in a comprehensive review article (Kaslow & Thompson, 1998) that evaluated interventions for depression in children and adolescents against the American Psychological Association Task Force criteria, two forms of cognitive-behavioral therapy (CBT) were found to be "probably effective treatments," although none of the interventions for depression were deemed, as yet, to meet the Association's higher standard for a *well-established* intervention.

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[7] The relationship between sexual orientation, depression, and suicidal thoughts and behavior is not well understood. Several studies suggest a link (Faullener & Cranston, 1998; Garofolo et al., 1998; Garofolo et al., 1999).

In studies that focused on relieving symptoms of depression in preadolescents, only one form of CBT met the criteria for a *probably effective* intervention. In the first study, the relative efficacy of two types of CBT—12-session group interventions based on either self-control therapy or behavior-solving therapy—were compared with a "waiting list" control group (Stark et al., 1987). Children responded to both CBT interventions with fewer symptoms of depression and anxiety, whereas the waiting list group exhibited minimal change. Because improvement was greatest with self-control therapy, this intervention was compared in a later study with a traditional counseling condition. Self-control therapy, enhanced by doubling the number of sessions, entailed social skills training, assertiveness training, relaxation training and imagery, and cognitive restructuring. Monthly family meetings were also added to both the experimental and control conditions. Children receiving self-control therapy reported fewer symptoms at 7-month followup (Stark et al., 1991).

Among the numerous studies of adolescents reviewed by Kaslow and Thomson (1998), one form of CBT—coping skills—was judged *probably efficacious*. This intervention, based on the "Coping with Depression" course, was developed originally in Oregon for adults by Lewinsohn and colleagues (Lewinsohn et al., 1996) and adapted by Clarke and colleagues (1992) for school-based programs to treat adolescent depression. Compared with controls on the waiting list, adolescents who received CBT had lower rates of depression, less self-reported depression, improvement in cognitions, and increased activity levels (Lewinsohn et al., 1990, 1996). To achieve *well-established* status, as defined by the American Psychological Association Task Force, the intervention has to be studied by another team of investigators—which has not as yet been done.

Pharmacological Treatment

Prior to 1996, the medications of choice for major depression in children and adolescents were the tricyclic antidepressants, a choice based on numerous studies in adults. However, 13 distinct trials in children and adolescents failed to demonstrate the efficacy of tricyclic antidepressants for younger ages. Tricyclic antidepressants also have a higher risk of toxicity than selective serotonin reuptake inhibitors (SSRIs) (Walsh et al., 1994; Kutcher, 1998). The current consensus is that tricyclic medications are not the medication of choice for depressed children and adolescents (Eisenberg, 1996; Fisher & Fisher, 1996).

Recent research indicates that young people with depressive disorders may respond more favorably to SSRIs than to tricyclic antidepressants. The first SSRI tested in children and adolescents was fluoxetine. In a study of 96 outpatients over 8 weeks, 56 percent receiving fluoxetine and 33 percent receiving placebo were "much" or "very much" improved on the Clinical Global Improvement Scale. Benefits were comparable across age groups. Complete symptom remission occurred for 31 percent of fluoxetine-treated patients compared with 23 percent of placebo-treated patients (Emslie et al., 1997). A recent open trial of fluoxetine for adolescents hospitalized for treatment of major depression found it to decrease depression scores more effectively than imipramine, a tricyclic antidepressant (Strober et al., 1999), with the further advantage that fluoxetine was well tolerated.

The safety of a second SSRI, paroxetine, was demonstrated in a multicenter double-blind placebo-controlled trial. Paroxetine was compared with imipramine and placebo in 275 adolescents who met the DSM-IV criteria for major depression. Preliminary results indicate that, mostly because of side effects, one-third of imipramine patients withdrew from the study, a proportion significantly higher than that for paroxetine (10 percent) and placebo (7 percent) (Wagner et al., 1998). One of the co-investigators of this study noted that paroxetine's efficacy was superior to that of imipramine and placebo on the Clinical Global Improvement Scale (Graham Emslie, personal communication, October 1998). However, final conclusions about the benefit of this second SSRI must await publication of the outcomes of this multicenter study.

In summary, psychosocial interventions for depressed children and adolescents indicate great promise, with several types of cognitive-behavioral therapy for the child or adolescent leading the way. With respect to pharmacotherapy, new studies attest to the safety and efficacy of two SSRIs. These promising findings are being extended in the recently begun NIMH-funded Treatment of Adolescents with Depression study.

Bipolar Disorder

Pharmacological Treatment

The treatment of bipolar disorder entails treating symptoms of both depression and mania. For decades, lithium has been the well-researched mainstay treatment for mania in adults. Mania in bipolar disorder of children is also treated with lithium, although the relevant research on children lags behind that on adults. Only in recent years have researchers begun to study lithium in children and adolescents, with good clinical response. Open trials of lithium were conducted in the late 1980s (Varanka et al., 1988; Strober et al., 1990). More recently, lithium proved to be more effective than placebo in treating adolescents who were bipolar and substance dependent (Geller et al., 1998).

Children experience the same safety problems with lithium as do adults: toxicity and impairment of renal and thyroid functioning (Geller & Luby, 1997). Lithium is therefore not recommended for families unable to keep regular appointments that would ensure monitoring of serum lithium levels and of adverse events. Patients who discontinue taking the drug have a high relapse rate (Strober et al., 1990).

As yet, there are no controlled studies on a number of other psychotropic agents also used clinically in children and adolescents with bipolar disorder, including valproate, carbamazepine, methylphenidate, and low-dose chlorpromazine (Campbell & Cueva, 1995; Geller & Luby, 1997).

Suicide

Psychotherapeutic Treatments

Suicidal children and adolescents report feelings of intense emotional distress involving depression, anger, anxiety, hopelessness, and worthlessness and an inability to change problematic, frustrating circumstances or to find a solution to their problems (Kienhorst et al., 1995; Ohring et al., 1996). They feel so distraught that they often respond impulsively to their despair. Psychotherapeutic techniques aim to decrease such intolerable feelings and thoughts and to re-orient the cognitive and emotional perspectives of the suicidal child or adolescent (Kernberg, 1994; Spirito, 1997).

Cognitive-behavioral therapy (CBT) may be a useful intervention, considering that suicidal children and adolescents often experience negative cognitions about themselves, their environment, and their futures. Recent research suggests that CBT may be more effective than systemic behavior family therapy or individual nondirective supportive therapy in reducing depressive symptoms associated with suicidal ideation (Brent et al., 1997). Such treatment can focus on re-attribution of precipitating issues for suicidal behavior and enable the suicidal child or adolescent to rank stresses and to consider avenues of problem-solving (Rotheram-Borus et al., 1994; Brent et al., 1997; Spirito, 1997).

Interpersonal conflicts are important stresses related to the risk imparted by poor social adjustment of potentially suicidal children and adolescents. Treatment of interpersonal strife may significantly reduce suicidal risk. Recent research into the efficacy of interpersonal psychotherapy of depressed adolescents suggests beneficial effects (Kaslow & Thompson, 1998); it is a treatment that may be modified to address the risk factor issues related to interpersonal loss, conflicts, and need for restitution often reported by children and adolescents with suicidal tendencies.

A significant class of risk factors for suicide involves family discord, which is characterized by poor communication, disagreements, and lack of cohesive values and goals and of common activities (de Long, 1992; Miller et al., 1992; Wagner, 1997). Suicidal children and adolescents often feel that they are isolated within the family, exhibit problems in independence, and view themselves as expendable to the family, a perception that is a motivating force for self-annihilation (Sabbath, 1969; Pfeffer, 1986; Miller et al., 1992). Family intervention with suicidal children and adolescents is an important method to decrease such problems and to enhance effective family problem-solving and conflict resolution, so that blame is not directed toward the suicidal child or adolescent. Cognitive-behavioral approaches with suicidal children and adolescents and their families aim to reframe their understanding of family problems, alter the family style of maladaptive problem-solving techniques, and encourage positive family interactions (Rotheram-Borus et al., 1994). Time-limited home-based intervention to reduce suicidal ideation in children and adolescents and to improve family functioning has been reported to have limited efficacy for children and adolescents without major depressive disorder (Harrington et al., 1998). Psychoeducational approaches to reduce the extent of expressed anger may be helpful in lowering risk for suicidal behavior in children and adolescents (Fristad et al., 1996).

Psychopharmacological Treatments

There is a dearth of research on the efficacy of pharmacological treatments for reducing suicidal thoughts or preventing suicide in children and adolescents. Most of the research on pharmacotherapies has been conducted in adults. In depressed adults, SSRIs have been found to reduce suicidal ideation (Letizia et al., 1996; Wernicke et al., 1997) and to reduce the frequency of suicide attempts in nondepressed patients who had previously made at least one suicide attempt (Verkes et al., 1998). In a controlled trial of the experimental neuroleptic drug flupenthixol, researchers noted a significant reduction in suicide-attempt behavior in adults who had made numerous previous attempts (Montgomery & Montgomery, 1982). Similar studies have yet to be conducted on adolescents, although trials of SSRIs in depressed adolescents suggest that these drugs are effective for treating depression and for reducing suicidal ideas also in this age group (Emslie et al., 1997; Ryan & Varma, 1998). Because placebo-controlled, methodologically appropriate studies of tricyclic antidepressants have failed to find a significant effect in depressed children and adolescents (Ryan & Varma, 1998), it is reasonable to regard SSRIs as a first-choice medication in treating depressed suicidal children and adolescents (also see American Academy of Child and Adolescent Psychiatry, 1998). In contrast to tricyclic antidepressants, SSRIs have low lethal potential when taken in overdoses (Ryan & Varma, 1998).

In adults with major depressive disorder, controlled research suggests that lithium reduces suicide risk (Thies-Flechtner et al., 1996), but this has not yet been demonstrated in children and adolescents. Clinicians should be cautious about prescribing medications that may reduce self-control, such as the benzodiazepines, amphetamines, and phenobarbital. These drugs also have a high lethal potential if taken in overdose (Carlsten et al., 1996).

Intervention After a Suicidal Death of a Relative, Friend, or Acquaintance

The suicidal death of a relative or acquaintance may increase the risk for childhood or adolescent suicidal behavior and other dysphoric states (Brent et al., 1992, 1994; Pfeffer et al., 1994, 1997; Clark & Goebel, 1996). Major depression, post-traumatic stress disorder, and suicidal ideation often occur after the death of an adolescent friend or acquaintance and relative (Brent et al., 1992, 1994, 1996).

The goal of the clinician is to decrease the likelihood that a child or adolescent comes to view the suicidal behavior of the deceased as a coping strategy in dealing with adversity (Brent et al., 1997). Psychoeducational counseling may reduce the risk for suicidal behavior in these circumstances. Intervention is also needed to decrease the child's or teen's personal sense of guilt, trauma, and social isolation. This treatment can be given in individual meetings, at group sessions with other teens, or in conjunction with parents who need help to support the adaptive capacities of their children and adolescents. School professionals sometimes offer programs of this kind and can be invaluable in identifying grieving friends who may need help.

Community-Based Suicide Prevention

The principal public health approaches to suicide prevention have been (1) crisis hotlines[*]; (2) restrictions covering access to suicide methods; (3) media counseling to minimize imitative suicide; (4) indirect case-finding by educating potential gate-keepers, teachers, parents, and peers to identify the warning signs of an impending suicide; (5) direct case-finding among high school or college students or among the patients of primary practitioners by screening for conditions that place teens at risk for suicide; and (6) training professionals to improve recognition and treatment of mood disorders. As discussed below, the level of evidence for these strategies varies. There is more support for direct case-finding and improved recognition and treatment of mood disorders than for the other strategies.

Crisis Hotlines

Although crisis hotlines are available almost everywhere in the United States, research has failed to show that they reduce the incidence of suicide (Bleach & Clairborn, 1974; Apsler & Hodas, 1976; Miller et al., 1984; Shaffer et al., 1990a, 1990b). Possible reasons for this are that actively suicidal individuals (males and individuals with an acute mental disturbance) do not call hotlines because they are acutely disturbed, preoccupied, or intent on not being deflected from their intended course of action (Shaffer et al., 1989). Hotlines are often busy, and there may be a long wait before a call is answered, so that callers disconnect; the advice individuals get on calling a hotline may be stereotyped, inappropriate for an individual's needs, and perceived as unhelpful by the caller. Gender preferences in seeking help result in the large majority of callers being females, whereas males are at greatest risk for suicide. While each of these deficiencies is potentially modifiable, there have been no systematic attempts to do so.

Method Restriction

Method preference for suicide varies by gender and by nationality. In the United States, the most common method for committing suicide is by firearms, and it has been suggested that reducing firearms availability will reduce the incidence of suicide (Moscicki, 1995). However, a natural experiment in Great Britain suggests this is unlikely. The favored suicide method, self-asphyxiation with coal gas, became impossible after the introduction of natural gas. This resulted in a marked but short-lived decline in the suicide rate. Within a decade, the suicide rate had returned to previous levels, and suicides were being committed by other means (Farberow, 1985). Although reducing access to firearms with gun-security laws reduces accidental deaths from firearms (Cummings et al., 1997), there is no evidence to date that such laws have a significant impact on suicides attributable to firearms.

Media Counseling

Even though it appears prudent for reporters and editors to minimize coverage of youth suicide in general and attention to individual suicides (O'Carroll & Potter, 1994), there is as yet no evidence that these guidelines, issued by the Centers for Disease Control and Prevention, are effective in reducing the suicide rate.

Indirect Case-Finding Through Education

Controlled studies have failed to show that classes for high school students about suicide increase students' help-seeking behavior when they are troubled or depressed (Spirito et al., 1988; Shaffer et al., 1991; Vieland et al., 1991). On the other hand, there is evidence that previously suicidal adolescents are upset by exposure to such classes (Shaffer et al., 1990a, 1990b), even though this does not necessarily lead to a suicide attempt. Such educational programs seem, therefore, to be both an ineffective mode of case-finding and to carry with them an unjustified risk of activating suicidal thoughts.

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[*] Crisis hotlines are only one of the services offered through crisis services, a topic discussed subsequently.

Direct Case-Finding

Judging from the high response rate to surveys about suicidal attempts and ideation (National Center for Health Statistics, 1997), adolescents will provide accurate information about their own suicidal thoughts and/or behaviors if asked directly in a nonthreatening way. A sensible approach to suicide prevention that needs further study, therefore, is to screen systematically 15- to 19-year-olds (the age group at greatest risk) for (1) previous suicide attempts; (2) recent, serious, suicidal preoccupations; (3) depression; or (4) complications of substance or alcohol use. Clearly, screening programs need to go beyond identifying a teen with a high-risk profile. Youth identified in this way should be referred for evaluation and, if necessary, treatment. Contingency arrangements may need to be made to assist uninsured adolescents with help if it is needed (Shaffer & Craft, 1999).

Aggressive Treatment of Mood Disorders

Preliminary and as yet unreplicated studies in Sweden (Rihmer et al., 1995) suggest that education of primary medical practitioners to better identify the characteristics of mood disorders and to treat these effectively produced a significant reduction in suicide and suicide-attempt rates. Although the optimal treatment of adolescent depression is not yet as well understood as that of adult depression, this is an option that may prove to be useful.

Air Force Suicide Prevention Program—A Community Approach

Combining many of the approaches for adolescents described above, the Air Force Surgeon General developed and implemented a community approach to suicide prevention for older adolescents and young adults on active duty. The program involved education on suicide risk awareness, reducing barriers to mental health services, and stigma-reducing efforts.[9]

Other Mental Disorders in Children and Adolescents

Anxiety Disorders

The combined prevalence of the group of disorders known as anxiety disorders is higher than that of virtually all other mental disorders of childhood and adolescence (Costello et al., 1996). The 1-year prevalence in children ages 9 to 17 is 13 percent (Table 3-1). This section furnishes brief overviews of several anxiety disorders: separation anxiety disorder, generalized anxiety disorder, social phobia, and obsessive-compulsive disorder. Treatments for all but the latter are grouped together below.

Separation Anxiety Disorder

Although separation anxieties are normal among infants and toddlers, they are not appropriate for older children or adolescents and may represent symptoms of separation anxiety disorder. To reach the diagnostic threshold for this disorder, the anxiety or fear must cause distress or affect social, academic, or job functioning and must last at least 1 month (DSM-IV). Children with separation anxiety may cling to their parent and have difficulty falling asleep by themselves at night. When separated, they may fear that their parent will be involved in an accident or taken ill, or in some other way be "lost" to the child forever. Their need to stay close to their parent or home may make it difficult for them to attend school or camp, stay at friends' houses, or be in a room by themselves. Fear of separation can lead to dizziness, nausea, or palpitations (DSM-IV).

Separation anxiety is often associated with symptoms of depression, such as sadness, withdrawal, apathy, or difficulty in concentrating, and such children often fear that they or a family member might die.

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[9] In 1995, prior to implementation, suicide rates were almost 16 per 100,000; following 3 years of exposure to the program, suicide rates fell to below 2 per 100,000 (Air Force Surgeon General, personal communication, 1999).

Young children experience nightmares or fears at bedtime.

About 4 percent of children and young adolescents suffer from separation anxiety disorder (DSM-IV). Among those who seek treatment, separation anxiety disorder is equally distributed between boys and girls. In survey samples, the disorder is more common in girls (DSM-IV). The disorder may be overdiagnosed in children and teenagers who live in dangerous neighborhoods and have reasonable fears of leaving home.

The remission rate with separation anxiety disorder is high. However, there are periods where the illness is more severe and other times when it remits. Sometimes the condition lasts many years or is a precursor to panic disorder with agoraphobia. Older individuals with separation anxiety disorder may have difficulty moving or getting married and may, in turn, worry about separation from their own children and partner.

The cause of separation anxiety disorder is not known, although some risk factors have been identified. Affected children tend to come from families that are very close-knit. The disorder might develop after a stress such as death or illness in the family or a move. Trauma, especially physical or sexual assault, might bring on the disorder (Goenjian et al., 1995). The disorder sometimes runs in families, but the precise role of genetic and environmental factors has not been established. The etiology of anxiety disorders is more thoroughly discussed in Chapter 4.

Generalized Anxiety Disorder

Children with generalized anxiety disorder (or overanxious disorder of childhood) worry excessively about all manner of upcoming events and occurrences. They worry unduly about their academic performance or sporting activities, about being on time, or even about natural disasters such as earthquakes. The worry persists even when the child is not being judged and has always performed well in the past. Because of their anxiety, children may be overly conforming, perfectionist, or unsure of themselves. They tend to redo tasks if there are any imperfections. They tend to seek approval and need constant reassurance about their performance and their anxieties (DSM-IV). The 1-year prevalence rate for all generalized anxiety disorder sufferers of all ages is approximately 3 percent. The lifetime prevalence rate is about 5 percent (DSM-IV).

About half of all adults seeking treatment for this disorder report that it began in childhood or adolescence, but the proportion of children with this disorder who retain the problem into adulthood is unknown. The remission rate is not thought to be as high as that of separation anxiety disorder.

Social Phobia

Children with social phobia (also called social anxiety disorder) have a persistent fear of being embarrassed in social situations, during a performance, or if they have to speak in class or in public, get into conversation with others, or eat, drink, or write in public. Feelings of anxiety in these situations produce physical reactions: palpitations, tremors, sweating, diarrhea, blushing, muscle tension, etc. Sometimes a full-blown panic attack ensues; sometimes the reaction is much more mild. Adolescents and adults are able to recognize that their fear is unreasonable or excessive, although this recognition does not prevent the fear. Children, however, might not recognize that their reaction is excessive, although they may be afraid that others will notice their anxiety and consider them odd or babyish.

Young children do not articulate their fears, but may cry, have tantrums, freeze, cling, appear extremely timid in strange social settings, shrink from contact with others, stay on the side during social events, and try to stay close to familiar adults. They may fall behind in school, avoid school completely, or avoid social activities among children their age. The avoidance of the fearful situations or worry preceding the feared event may last for weeks and interfere with the individual's daily routine, social life, job, or school. They may find it impossible to speak in social situations or in the presence of unfamiliar people (for review of social phobia, see DSM-IV; Black et al., 1997).

Social phobia is common, the lifetime prevalence ranging from 3 to 13 percent, depending on how great the fear is and on how many different situations induce the anxiety (DSM-IV; Black et al., 1997). In survey studies, the majority of those with the disorder were found to be female (DSM-IV). Often the illness is lifelong, although it may become less severe or completely remit. Life events may reassure the individual or exacerbate the anxiety and disorder.

Treatment of Anxiety

Although anxiety disorders are the most common disorder of youth, there is relatively little research on the efficacy of psychotherapy (Kendall et al., 1997). For childhood phobias, contingency management[10] was the only intervention deemed to be *well-established*, according to an evaluation by Ollendick and King (1998), which applied the American Psychological Association Task Force criteria (noted earlier) Several psychotherapies are *probably efficacious* for treating phobias: systematic desensitization[11]; modeling, based on research by Bandura and colleagues, which capitalizes on an observational learning technique (Bandura, 1971; see also Chapter 2); and several cognitive-behavioral therapy (CBT) approaches (Ollendick & King, 1998).

CBT, as pioneered by Kendall and colleagues (Kendall et al., 1992; Kendall, 1994), is deemed by the American Psychological Association Task Force as *probably efficacious*. It has four major components: recognizing anxious feelings, clarifying cognitions in anxiety-provoking situations,[12] developing a plan for coping, and evaluating the success of coping strategies. A more recent study in Australia added a parent component to CBT, which enhanced reduction in post-treatment anxiety disorder significantly compared with CBT alone (Barrett et al., 1996). However, none of the interventions identified above as *well-established* or *probably efficacious* has, for the most part, been tested in real-world settings.

In addition, psychodynamic treatment to address underlying fears and worries can be helpful, and behavior therapy may reduce the child's fear of separation or of going to school; however, the experimental support for these approaches is limited.

Preliminary research suggests that selective serotonin reuptake inhibitors may provide effective treatment of separation anxiety disorder and other anxiety disorders of childhood and adolescence. Two large-scale randomized controlled trials are currently being undertaken (Greenhill, 1998a, 1998b). Neither tricyclic antidepressants nor benzodiazepines have been shown to be more effective than placebo in children (Klein et al., 1992; Bernstein et al., 1998).

Obsessive-Compulsive Disorder

Obsessive-compulsive disorder (OCD), which is classified in DSM-IV as an anxiety disorder, is characterized by recurrent, time-consuming obsessive or compulsive behaviors that cause distress and/or impairment. The obsessions may be repetitive intrusive images, thoughts, or impulses. Often the compulsive behaviors, such as hand-washing or cleaning rituals, are an attempt to displace the obsessive thoughts (DSM-IV). Estimates of prevalence range from 0.2 to 0.8 percent in children, and up to 2% of adolescents (Flament et al., 1998).

There is a strong familial component to OCD, and there is evidence from twin studies of both genetic susceptibility and environmental influences. If one twin has OCD, the other twin is more likely to have OCD if the children are identical twins rather than fraternal twin pairs. OCD is increased among first-degree relatives of children with OCD, particularly among fathers (Lenane et al., 1990). It does not appear that the child is simply imitating the relative's behavior, because children who develop OCD tend to have symptoms different from those of relatives with the disease (Leonard et al., 1997). Many adults with either childhood- or adolescent-onset of OCD show evidence of abnormalities in a neural network known as the orbitofrontal-striatal area (Rauch & Savage, 1997; Grachev et al., 1998).

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[10] Contingency management attempts to alter behavior by manipulating its consequences through the behavioral principles of shaping, positive reinforcement, and extinction.

[11] A technique that trains people to "unlearn" fears by presentation of fearful stimuli along with nonfearful stimuli.

[12] This refers to understanding how cognitions are being distorted.

Recent research suggests that some children with OCD develop the condition after experiencing one type of streptococcal infection (Swedo et al., 1995). This condition is referred to by the acronym PANDAS, which stands for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections. Its hallmark is a sudden and abrupt exacerbation of OCD symptoms after a strep infection. This form of OCD occurs when the immune system generates antibodies to the streptococcal bacteria, and the antibodies cross-react with the basal ganglia[13] of a susceptible child, provoking OCD (Garvey et al., 1998). In other words, the cause of this form of OCD appears to be antibodies directed against the infection mistakenly attacking a region of the brain and setting off an inflammatory reaction.

The selective serotonin reuptake inhibitors appear effective in ameliorating the symptoms of OCD in children, although more clinical trials have been done with adults than with children. Several randomized, controlled trials revealed SSRIs to be effective in treating children and adolescents with OCD (Flament et al., 1985; DeVeaugh-Geiss et al., 1992; Riddle et al., 1992, 1998). The appropriate duration of treatment is still being studied. Side effects are not inconsequential: dry mouth, somnolence, dizziness, fatigue, tremors, and constipation occur at fairly high rates. Cognitive-behavioral treatments also have been used to treat OCD (March et al., 1997), but the evidence is not yet conclusive.

Autism

Autism, the most common of the pervasive developmental disorders (with a prevalence of 10 to 12 children per 10,000 [Bryson & Smith, 1998]), is characterized by severely compromised ability to engage in, and by a lack of interest in, social interactions. It has roots in both structural brain abnormalities and genetic predispositions, according to family studies and studies of brain anatomy. The search for genes that predispose to autism is considered an extremely high research priority for the National Institute of Mental Health (NIMH, 1998). Although the reported association between autism and obstetrical hazard may be due to genetic factors (Bailey et al., 1995), there is evidence that several different causes of toxic or infectious damage to the central nervous system during early development also may contribute to autism. Autism has been reported in children with fetal alcohol syndrome (Aronson et al., 1997), in children who were infected with rubella during pregnancy (Chess et al., 1978), and in children whose mothers took a variety of medications that are known to damage the fetus (Williams & Hersh, 1997).

Cognitive deficits in social perception likely result from abnormalities in neural circuitry. Children with autism have been studied with several imaging techniques, but no strongly consistent findings have emerged, although abnormalities in the cerebellum and limbic system (Rapin & Katzman, 1998) and larger brains (Piven, 1997) have been reported. In one small study (Zilbovicius et al., 1995), evidence of delayed maturation of the frontal cortex was found. The evidence for genetic influences include a much greater concordance in identical than in fraternal twins (Cook, 1998).

Treatment

Because autism is a severe, chronic developmental disorder, which results in significant lifelong disability, the goal of treatment is to promote the child's social and language development and minimize behaviors that interfere with the child's functioning and learning. Intensive, sustained special education programs and behavior therapy early in life can increase the ability of the child with autism to acquire language and ability to learn. Special education programs in highly structured environments appear to help the child acquire self-care, social, and job skills. Only in the past decade have studies shown positive outcomes for very young children with autism. Given the severity of the impairment, high intensity of service needs, and costs (both human and financial), there has been an ongoing search for effective treatment.

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[13] Basal ganglia are groups of neurons responsible for motor and impulse control, attention, and regulation of mood and behavior.

Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior. A well-designed study of a psychosocial intervention was carried out by Lovaas and colleagues (Lovaas, 1987; McEachin et al., 1993). Nineteen children with autism were treated intensively with behavior therapy for 2 years and compared with two control groups. Followup of the experimental group in first grade, in late childhood, and in adolescence found that nearly half the experimental group but almost none of the children in the matched control group were able to participate in regular schooling. Up to this point, a number of other research groups have provided at least a partial replication of the Lovaas model (see Rogers, 1998).

Several uncontrolled studies of comprehensive center-based programs have been conducted, focusing on language development and other developmental skills. A comprehensive model, Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), demonstrated short-term gains for preschoolers with autism who received daily TEACCH home-teaching sessions, compared with a matched control group (Ozonoff & Cathcart, 1998). A review of other comprehensive, center-based programs has been conducted, focusing on elements considered critical to school-based programs, including minimum hours of service and necessary curricular components (Dawson & Osterling, 1997).

The antipsychotic drug, haloperidol, has been shown to be superior to placebo in the treatment of autism (Perry et al., 1989; Locascio et al., 1991), although a significant number of children develop dyskinesias[14] as a side effect (Campbell et al., 1997). Two of the SSRIs, clomipramine (Gordon et al., 1993) and fluoxetine (McDougle et al., 1996), have been tested, with positive results, except in young autistic children, in whom clomipramine was not found to be therapeutic, and who experienced untoward side effects (Sanchez et al., 1996). Of note, preliminary studies of some of the newer antipsychotic drugs suggest that they may have fewer side effects than conventional antipsychotics such as haloperidol, but controlled studies are needed before firm conclusions can be drawn about any possible advantages in safety and efficacy over traditional agents.

Disruptive Disorders

Disruptive disorders, such as oppositional defiant disorder and conduct disorder, are characterized by antisocial behavior and, as such, seem to be a collection of behaviors rather than a coherent pattern of mental dysfunction. These behaviors are also frequently found in children who suffer from attention-deficit/hyperactivity disorder, another disruptive disorder, which is discussed separately in this chapter. Children who develop the more serious conduct disorders often show signs of these disorders at an earlier age. Although it is common for a very young children to snatch something they want from another child, this kind of behavior may herald a more generally aggressive behavior and be the first sign of an emerging oppositional defiant or conduct disorder if it occurs by the ages of 4 or 5 and later. However, not every oppositional defiant child develops conduct disorder, and the difficult behaviors associated with these conditions often remit.

Oppositional defiant disorder (ODD) is diagnosed when a child displays a persistent or consistent pattern of defiance, disobedience, and hostility toward various authority figures including parents, teachers, and other adults. ODD is characterized by such problem behaviors as persistent fighting and arguing, being touchy or easily annoyed, and deliberately annoying or being spiteful or vindictive to other people. Children with ODD may repeatedly lose their temper, argue with adults, deliberately refuse to comply with requests or rules of adults, blame others for their own mistakes, and be repeatedly angry and resentful. Stubbornness and testing of limits are common. These behaviors cause significant difficulties with family and friends and at school or work (DSM-IV; Weiner, 1997). Oppositional defiant disorder is sometimes a precursor of conduct disorder (DSM-IV).

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[14] Dyskinesia is an impairment of voluntary movement, such that it becomes fragmentary or incomplete.

In different studies, estimates of the prevalence of ODD have ranged from 1 to 6 percent, depending on the population sample and the way the disorder was evaluated, but not depending on diagnostic criteria. Rates are lower when impairment criteria are more strict and when information is obtained from teachers and parents rather than from the children alone (Shaffer et al., 1996a). Before puberty, the condition is more common in boys, but after puberty the rates in both genders are equal.

In preschool boys, high reactivity, difficulty being soothed, and high motor activity may indicate risk for the disorder. Marital discord, disrupted child care with a succession of different caregivers, and inconsistent, unsupervised child-rearing may contribute to the condition.

Children or adolescents with *conduct disorder* behave aggressively by fighting, bullying, intimidating, physically assaulting, sexually coercing, and/or being cruel to people or animals. Vandalism with deliberate destruction of property, for example, setting fires or smashing windows, is common, as are theft; truancy; early tobacco, alcohol, and substance use and abuse; and precocious sexual activity. Girls with a conduct disorder are prone to running away from home and may become involved in prostitution. The behavior interferes with performance at school or work, so that individuals with this disorder rarely perform at the level predicted by their IQ or age. Their relationships with peers and adults are often poor. They have higher injury rates and are prone to school expulsion and problems with the law. Sexually transmitted diseases are common. If they have been removed from home, they may have difficulty staying in an adoptive or foster family or group home, and this may further complicate their development. Rates of depression, suicidal thoughts, suicide attempts, and suicide itself are all higher in children diagnosed with a conduct disorder (Shaffer et al., 1996b).

The prevalence of conduct disorder in 9- to 17-year-olds in the community varies from 1 to 4 percent, depending on how the disorder is defined (Shaffer et al., 1996a). Children with an early onset of the disorder, i.e., onset before age 10, are predominantly male. The disorder appears to be more common in cities than in rural areas (DSM-IV). Those with early onset have a worse prognosis and are at higher risk for adult antisocial personality disorder (DSM-IV; Rutter & Giller, 1984; Hendren & Mullen, 1997). Between a quarter and a half of highly antisocial children become antisocial adults.

The etiology of conduct disorder is not fully known. Studies of twins and adopted children suggest that conduct disorder has both biological (including genetic) and psychosocial components (Hendren & Mullen, 1997). Social risk factors for conduct disorder include early maternal rejection, separation from parents with no adequate alternative caregiver available, early institutionalization, family neglect, abuse or violence, parents' psychiatric illness, parental marital discord, large family size, crowding, and poverty (Loeber & Stouthamer-Loeber, 1986). These factors are thought to lead to a lack of attachment to the parents or to the family unit and eventually to lack of regard for the rules and rewards of society (Sampson & Laub, 1993). Physical risk factors for conduct disorder include neurological damage caused by birth complications or low birthweight, attention-deficit/hyperactivity disorder, fearlessness and stimulation-seeking behavior, learning impairments, autonomic underarousal, and insensitivity to physical pain and punishment. A child with both social deprivation and any of these neurological conditions is most susceptible to conduct disorder (Raine et al., 1998).

Since many of the risk factors for conduct disorder emerge in the first years of life, intervention must begin very early. Recently, screening instruments have been developed to enable earlier identification of risk factors and signs of conduct disorder in young children (Feil et al., 1995). Studies have shown a correlation between the behavior and attributes of 3-year-olds and the aggressive behavior of these children at ages 11 to 13 (Raine et al., 1998). Measurements of aggressive behaviors have been shown to be stable over time (Sampson & Laub, 1993). Training parents of high-risk children how to deal with the children's demands may help. Parents may need to be taught to reinforce appropriate behaviors and not harshly punish transgressing ones, and encouraged to find ways to increase the strength of the emotional ties between parent and child. Working with high-risk children on social interaction and providing academic help to reduce rates of school failure can help prevent some of the negative educational consequences of conduct disorder (Johnson & Breckenridge, 1982).

Treatment

Several psychosocial interventions can effectively reduce antisocial behavior in disruptive disorders. A recent review of psychosocial treatments for children and adolescents identified 82 studies conducted between 1966 and 1995 involving 5,272 youth (Brestan & Eyberg, 1998). The criterion for inclusion was that the child was in treatment for conduct problem behavior, based on displaying a symptom of conduct disorder or oppositional defiant disorder, rather than on a DSM diagnosis of either, although children did meet DSM criteria for one of these conditions in about one-third of the studies.

By applying criteria established by the American Psychological Association Task Force (see earlier) to the 82 studies, two treatments met criteria for *well-established* treatment and 10 for *probably efficacious* treatment. Two *well-established* treatments, both directed at training parents, succeeded in reducing problem behaviors. The two treatments were a parent training program based on the manual *Living With Children* (Bernal et al., 1980) and a videotape modeling parent training (Spaccarelli et al., 1992). The first teaches parents to reward desirable behaviors and ignore or punish deviant behaviors, based on principles of operant conditioning. The second provides a series of videotapes covering parent-training lessons, after which a therapist leads a group discussion of the videotape lessons. The identification of 12 treatments as *well-established* or *probably efficacious* is very encouraging because of the potential to intervene effectively with youth at high risk of poor outcomes. A new and promising approach for the treatment of conduct disorder is multisystemic therapy, an intensive home- and family-focused treatment that is described under Home-Based Services.

Despite strong enthusiasm for improving care for conduct-disordered youth, there are important groups of children, specifically girls and ethnic minority populations, who were not sufficiently represented in these studies to ensure that the identified treatments work for them. Other issues raised by Brestan and Eyberg (1998) are cost-effectiveness, the sufficiency of a given intervention, effectiveness over time, and the prevention of relapse.

No drugs have been demonstrated to be consistently effective in treating conduct disorder, although four drugs have been tested. Lithium and methylphenidate have been found (one double-blind placebo trial each) to reduce aggressiveness effectively in children with conduct disorder (Campbell et al., 1995; Klein et al., 1997b), but in two subsequent studies with the same design, the positive findings for lithium could not be reproduced (Rifkin et al., 1989; Klein, 1991). In one of the latter studies, methylphenidate was superior to lithium and placebo. A third drug, carbamazepine, was found in a pilot study to be effective, but multiple side effects were also reported (Kafantaris et al., 1992). The fourth drug, clonidine, was explored in an open trial, in which 15 of 17 patients showed a significant decrease in aggressive behavior, but there were also significant side effects that would require monitoring of cardiovascular and blood pressure parameters (Kemph et al., 1993).

Substance Use Disorders in Adolescents

Since the early 1990s there has been a "sharp resurgence" in the misuse of alcohol and other drugs by adolescents (Johnston et al., 1996). A recent review, focusing particularly on substance abuse and dependence, synthesizes research findings of the past decade (Weinberg et al., 1998). The authors review epidemiology, course, etiology, treatment, and prevention and discuss comorbidity with other mental disorders in adolescents. All of these issues are important to public health, but none is more relevant to this report than the co-occurrence of alcohol and other substance use disorders with other mental disorders in adolescents.

According to the National Comorbidity Study, 41 to 65 percent of individuals with a lifetime substance abuse disorder also have a lifetime history of at least one mental disorder, and about 51 percent of those with one or more lifetime mental disorders also have a lifetime history of at least one substance use disorder (Kessler et al., 1996). The rates are highest in the 15- to 24-year-old age group (Kessler et al., 1994). The cross-sectional data on association do not permit any conclusion about causality or clinical prediction (Kessler et al., 1996), but an appealing theory suggests that a subgroup of the population abuses drugs in an effort to self-medicate for the co-occurring mental disorder. Little is actually known about the role of mental disorders in increasing the risk of children and adolescents for misuse of alcohol and other drugs. Stress appears to play a role in both the process of addiction and the development of many of the comorbid conditions.

The review by Weinberg and colleagues (1998) provides more detail on epidemiology and assessment of alcohol and other drug use in adolescents and describes several effective treatment approaches for these problems. A meta-analysis and literature review (Stanton & Shadish, 1997) concluded that family-oriented therapies were superior to other treatment approaches and enhanced the effectiveness of other treatments. Multisystemic family therapy, discussed elsewhere in this chapter, is effective in reducing alcohol and other substance use and other severe behavioral problems among adolescents (Pickrel & Henggeler, 1996).

Eating Disorders

Eating disorders are serious, sometimes life-threatening, conditions that tend to be chronic (Herzog et al., 1999). They usually arise in adolescence and disproportionately affect females. About 3 percent of young women have one of the three main eating disorders: anorexia nervosa, bulimia nervosa, or binge-eating disorder (Becker et al., 1999). Binge-eating disorder is a newly recognized condition featuring episodic uncontrolled consumption, without compensatory activities, such as vomiting or laxative abuse, to avert weight gain (Devlin, 1996). Bulimia, in contrast, is marked by both binge eating and by compensatory activities. Anorexia nervosa is characterized by low body weight (< 85 percent of expected weight), intense fear of weight gain, and an inaccurate perception of body weight or shape (DSM-IV). Its mean age of onset is 17 years (DSM-IV).

The causes of eating disorders are not known with precision but are thought to be a combination of genetic, neurochemical, psychodevelopmental, and sociocultural factors (Becker et al., 1999; Kaye et al., 1999). Comorbid mental disorders are exceedingly common, but interrelationships are poorly understood. Comorbid disorders include affective disorders (especially depression), anxiety disorders, substance abuse, and personality disorders (Herzog et al., 1996). Anorexia nervosa has the most severe consequence, with a mortality rate of 0.56 percent per year (or 5.6 percent per decade) (Sullivan, 1995), a rate higher than that of almost all other mental disorders (Herzog et al., 1996). Mortality is from starvation, suicide, or electrolyte imbalance (DSM-IV). The mortality rate from anorexia nervosa is 12 times higher than that for other young women in the population (Sullivan , 1995).

Treatment of eating disorders entails psychotherapy and pharmacotherapy, either alone or in combination. Treatment of comorbid mental disorders also is important, as is treatment of medical complications. There are some controlled studies of the efficacy of specific treatments for *adults* with bulimia and binge-eating disorder (Devlin, 1996), but fewer for anorexia nervosa (Kaye et al., 1999). Controlled studies in adolescents are rare for any eating disorder (Steiner and Lock, 1998). Pharmacological studies in young *adult* women found conflicting evidence of benefit from antidepressants for anorexia and some reduction in the frequency of binge eating and purging with tricyclic antidepressants, monoamine oxidase inhibitors, and SSRIs (see Jimerson et al., 1993; Jacobi et al., 1997). Studies mostly of adult women find cognitive-behavioral therapy and interpersonal therapy to be effective for bulimia and binge-eating disorder

(Fairburn et al., 1993; Devlin, 1996; Becker et al., 1999). Clearly, more research is warranted for the treatment of eating disorders, especially because a sizable proportion of those with eating disorders have limited response to treatment (Kaye et al., 1999).

Services Interventions

Treatment Interventions

This section examines the effectiveness of such treatment interventions as outpatient, partial hospitalization/day, residential, inpatient treatments, and medication. Much of the research on their effectiveness deals with children's outcomes largely independent of diagnosis. As noted earlier in this chapter (see Treatment Strategies), practitioners and researchers previously shied away from diagnosis because of the inherent difficulty of making a diagnosis, concerns about labeling children, and the limited usefulness of DSM classifications for children. Each intervention was developed to treat a *host* of mental health conditions in children and adolescents. Each also was delivered in a wide range of settings. Over time, the combination of interventions and settings, with the exception of medication, became conceptualized as "treatments," which stimulated research on their effectiveness (Goldman, 1998). They are not, however, treatments in the conventional sense of the term because they are less specific than other treatments with respect to indications, intensity (i.e., "dose"), and elements of the intervention. There is little research describing treatment in actual clinical settings.

Outpatient Treatment

The term "outpatient treatment" covers a large variety of therapeutic approaches, with most falling into the broad theoretical categories of the psychodynamic, interpersonal, and behavioral psychotherapy. Outpatient psychotherapy is the most common form of treatment for children and adolescents, utilized annually by an estimated 5 to 10 percent of children and their families in the United States (Burns et al., 1998). It is also the most extensively studied intervention and, with over 300 studies, has the strongest research base (Weisz et al., 1998). Outpatient therapy is offered to individuals, groups, or families, usually in a clinic or private office. The duration of treatment varies from 6 to 12 weekly sessions to a year or longer. Newer outpatient interventions (e.g., case management, home-based therapy) that were developed more recently for youth with severe disorders are provided with greater frequency (i.e., daily) in the home, school, or community. Those interventions are reviewed later in this chapter.

The strongest support for the effectiveness of outpatient treatment comes from a series of meta-analyses. Meta-analyses are an important type of research methodology, described in Chapter 1, that enable one to combine research findings from separate studies. Nine meta-analyses, published between 1985 and 1995, probed the effectiveness of research on individual, group, and family therapy for children and adolescents (Casey & Berman, 1985; Hazelrigg et al., 1987; Weisz et al., 1987; Kazdin et al., 1990; Baer & Nietzel, 1991; Grossman & Hughes 1992; Shadish et al., 1993; Weisz & Weiss, 1993; Weisz et al., 1995). Although these meta-analyses vary in time period, age groups, and meta-analytic approach, they were largely restricted to studies of treatment given in a research clinical setting, and their findings are relatively consistent. The major findings indicated that the improvements with outpatient therapy are greater than those achieved without treatment; the treatment is highly effective, as was found in meta-analyses of adults (Brown, 1987); and the effects of treatment are similar, whether applied to problems such as anxiety, depression, or withdrawal (internalizing problems) or to hyperactivity and aggression (externalizing problems) (Kazdin, 1996).

Given strong evidence of efficacy for outpatient treatment, the question of applicability to real-world settings has been examined. A meta-analysis was performed on studies of the effectiveness of various types of outpatient treatment, regardless of whether their efficacy had been established through research (Weisz et al., 1995). The researchers were able to identify only nine studies of treated children in nonresearch clinical settings where therapy was a regular service of the clinic and was carried out by practicing clinicians. Those nine studies demonstrated little or no effect. Clearly, real-world therapy was found to be less effective than that provided through a research protocol. A variety of factors may account for the gap, including less attention in real-world settings to careful matching of patients with treatments, less adherence to a treatment protocol, and less followup care.

Partial Hospitalization/Day Treatment

Partial hospitalization, also called day treatment and partial care, has been a growing treatment modality for youth with mental disorders. Research on partial hospitalization as an alternative to inpatient treatment generally finds benefit from a structured daily environment that allows youth to return home at night to be with their family and peers.

Partial hospitalization is a specialized and intensive form of treatment that is less restrictive than inpatient care but is more intensive than the usual types of outpatient care (i.e., individual, family, or group treatment). The most frequently used type of partial hospitalization is an integrated curriculum combining education, counseling, and family interventions. The setting, be it a hospital, school, or clinic, may be tied to the theoretical orientation of the treatment, which ranges from psychoanalytic to behavioral. Partial hospitalization has also been used as a transitional service after either psychiatric hospitalization or residential treatment, at the point when the child no longer needs 24-hour care but is not ready to be integrated into the school system. It also is used to prevent institutional placement.

Overall, the research literature points to positive gains from adolescent use of day treatment, but most of the studies are uncontrolled. Gains relate to academic and behavioral improvement; reduction in, or delay of, hospital and residential placement; and a return to regular school for about 75 percent of patients (Baenen et al., 1986; Gabel & Finn, 1986). Day treatment programs are not being used as frequently as they might be because third-party payers are reluctant to support this form of treatment. They claim that the modality is ambiguous, that it induces demand among those who would not otherwise seek treatment, and that its length, treatment outcomes, and costs are unpredictable (Kiser et al., 1986). Research is needed to address these issues.

To date, the only controlled study of partial hospitalization compared outcomes for young children (ages 5 to 12) with disruptive behavior disorders who received intensive day treatment with children who received traditional outpatient treatment services (in fact, a waiting list control) (Grizenko et al., 1993). The results at 6 months favored day treatment in reducing behavior problems, decreasing symptoms, and improving family functioning.

Findings from uncontrolled studies of partial hospitalization are informative, although not conclusive. Based on approximately 20 studies, multiple benefits have been reported even over the long term (see reviews by Kutash & Rivera, 1996; Grizenko, 1997). In general, child behavior and family functioning improve following partial hospitalization. Findings for improved academic achievement are mixed and possibly suggest that implementation of school-based models should be considered. About three-fourths of youth are reintegrated into regular school, often with the help of special education or other school- or community-based services. Several uncontrolled studies found that day treatment could prevent youth from entering other costly placements (particularly inpatient and residential treatment centers), which suggests that partial hospitalization may reduce overall costs of treatment (Kutash & Rivera, 1996). Finally, family participation during and following day treatment is essential to obtaining and maintaining results (Kutash & Rivera, 1996).

Residential Treatment Centers

Residential treatment centers are the second most restrictive form of care (next to inpatient hospitalization) for children with severe mental disorders. Although used by a relatively small percentage (8 percent) of treated children, nearly one-fourth of the national outlay on child mental health is spent on care in these settings (Burns et al., 1998).

However, there is only weak evidence for their effectiveness.

A residential treatment center (RTC) is a licensed 24-hour facility (although not licensed as a hospital), which offers mental health treatment. The types of treatment vary widely; the major categories are psychoanalytic, psychoeducational, behavioral management, group therapies, medication management, and peer-cultural. Settings range from structured ones, resembling psychiatric hospitals, to those that are more like group homes or halfway houses. While formerly for long-term treatment (e.g., a year or more), RTCs under managed care are now serving more seriously disturbed youth for as briefly as 1 month for intensive evaluation and stabilization.

Concerns about residential care primarily relate to criteria for admission; inconsistency of community-based treatment established in the 1980s; the costliness of such services (Friedman & Street, 1985); the risks of treatment, including failure to learn behavior needed in the community; the possibility of trauma associated with the separation from the family; difficulty reentering the family or even abandonment by the family; victimization by RTC staff; and learning of antisocial or bizarre behavior from intensive exposure to other disturbed children (Barker, 1998). These concerns are discussed below.

In the past, admission to an RTC has been justified on the basis of community protection, child protection, and benefits of residential treatment per se (Barker, 1982). However, none of these justifications have stood up to research scrutiny. In particular, youth who display seriously violent and aggressive behavior do not appear to improve in such settings, according to limited evidence (Joshi & Rosenberg, 1997). One possible reason is that association with delinquent or deviant peers is a major risk factor for later behavior problems (Loeber & Farrington, 1998). Moreover, community interventions that target change in peer associations have been found to be highly effective at breaking contact with violent peers and reducing aggressive behaviors (Henggeler et al., 1998). Although removal from the community for a time may be necessary for some, there is evidence that highly targeted behavioral interventions provided on an outpatient basis can ameliorate such behaviors (Brestan & Eyberg, 1998). For children in the second category (i.e., those needing protection from themselves because of suicide attempts, severe substance use, abuse, or persistent running away), it is possible that a brief hospitalization for an acute crisis or intensive community-based services may be more appropriate than an RTC. An intensive long-term program such as an RTC with a high staff to child ratio may be of benefit to some children, especially when sufficient supportive services are not available in their communities. In short, there is a compelling need to clarify criteria for admission to RTCs (Wells, 1991). Previous criteria have been replaced and strengthened (i.e., with an emphasis on resources needed after discharge) by the National Association of Psychiatric Treatment Centers for Children (1990).

The evidence for outcomes of residential treatment comes from research published largely in the 1970s and 1980s and, with three exceptions, consists of uncontrolled studies (see Curry, 1991).

Of the three controlled studies of RTCs, the first evaluated a program called Project Re-Education (Re-Ed). Project Re-Ed, a model of residential treatment developed in the 1960s, focuses on training teacher-counselors, who are backed up by consultant mental health specialists. Project Re-Ed schools are located within communities, facilitating therapeutic work with the family and allowing the child to go home on weekends. Camping also is an important component of the program, inspired by the Outward Bound Schools in England. The first published study of Project Re-Ed compared outcomes for adolescent males in Project Re-Ed with untreated disturbed adolescents and with nondisturbed adolescents. Treated adolescents improved in self-esteem, control of impulsiveness, and internal control compared with untreated adolescents, according to ratings by Project Re-Ed staff and by families (Weinstein, 1974). A 1988 followup study of Project Re-Ed found that when adjustment outcomes were maintained at 6 months after discharge from Project Re-Ed, those outcomes were predicted more by community factors at admission (e.g., condition of the family and school, supportiveness of the local community) than by client factors (e.g., diagnosis, school achievement, age, IQ). This suggested that interventions in the child's community might be as effective as placement in the treatment setting (Lewis, 1988).

The only other controlled study compared an RTC with therapeutic foster care through the Parent Therapist Program. Both client groups shared comparable backgrounds and made similar progress in their respective treatment program. However, the residential treatment cost twice as much as therapeutic foster care (Rubenstein et al., 1978).

Despite strong caveats about the quality, sophistication, and import of uncontrolled studies, several consistent findings have emerged. For most children (60 to 80 percent), gains are reported in areas such as clinical status, academic skills, and peer relationships. Whether gains are sustained following treatment appears to depend on the supportiveness of the child's post-discharge environment (Wells, 1991). Several studies of single institutions report maintenance of benefits from 1 to 5 years later (Blackman et al., 1991; Joshi & Rosenberg, 1997). In contrast, a large longitudinal six-state study of children in publicly funded RTCs found at the 7-year followup that 75 percent of youth treated at an RTC had been either readmitted to a mental health facility (about 45 percent) or incarcerated in a correctional setting (about 30 percent) (Greenbaum et al., 1998).

In summary, youth who are placed in RTCs clearly constitute a difficult population to treat effectively. The outcomes of not providing residential care are unknown. Transferring gains from a residential setting back into the community may be difficult without clear coordination between RTC staff and community services, particularly schools, medical care, or community clinics. Typically, this type of coordination or aftercare service is not available upon discharge. The research on RTCs is not very enlightening about the potential to substitute RTC care for other levels of care, as this requires comparisons with other interventions. Given the limitations of current research, it is premature to endorse the effectiveness of residential treatment for adolescents. Moreover, research is needed to identify those groups of children and adolescents for whom the benefits of residential care outweigh the potential risks.

Inpatient Treatment

Inpatient hospitalization is the most restrictive type of care in the continuum of mental health services for children and adolescents. Questions about excessive and inappropriate use of hospitals were raised in the early 1980s (Knitzer, 1982) and clearly documented thereafter in rising admission rates from the 1980s into the mid-1990s, without evidence of increased social or clinical need for such treatment (Weller et al., 1995). Inpatient care consumes about half of child mental health resources, based on the latest estimate available (Burns, 1991), but it is the clinical intervention with the weakest research support. Nevertheless, because some children with severe disorders *do* require a highly restrictive treatment environment, hospitals are expected to remain an integral component of mental health care (Singh et al., 1994). More concerted attention to the risks and benefits of hospital use is critical, however, along with development of community-based alternative services.

Research on inpatient treatment mostly consists of uncontrolled studies (Curry, 1991). Factors that are likely to predict benefit have been identified from such studies. Beneficial factors were found to include higher child intelligence; the quality of family functioning and family involvement in treatment; specific characteristics of treatment (e.g., completion of treatment program and planned discharge); and the use of aftercare services. Neither age nor gender affected prognosis after hospitalization. The prognosis was poor for several clinical characteristics, including children with a psychotic diagnosis and antisocial features with conduct disorder (Kutash & Rivera, 1996).

Only three controlled studies evaluated the effectiveness of inpatient treatment: one that randomized antisocial children to specific interventions on an inpatient unit (Kazdin et al., 1987a, 1987b) and two older clinical trials (Flomenhaft, 1974; Winsberg et al., 1980). All three studies demonstrated that community care was at least as effective as inpatient treatment.

More recently there have been preliminary favorable findings from a randomized trial of inpatient treatment versus multisystemic therapy (MST), an intensive home-based intervention. For example, MST was more effective than psychiatric hospitalization in reducing antisocial behavior, improving family structure and cohesion, improving social relationships, and keeping children in school and out of institutions (after the initial period when the control group was in the hospital). Hospitalized youth reported improved self-esteem, and youth in both treatment conditions showed comparable decreases in emotional distress (Henggeler et al., 1998). A great deal more research is needed on inpatient hospitalization, as it is by far the costliest and most restrictive form of care. Recent changes in health care management have resulted in short lengths of stay for children and adolescents. Preliminary results from the study of MST indicate that intensive home-based services may be a viable alternative to hospitalization. However, even when such services are available, there may be a need for brief 24-hour stabilization units for handling crises (see Crisis Services).

Newer Community-Based Interventions

Since the 1980s, the field of children's mental health has witnessed a shift from institutional to community-based interventions. The forces behind this transformation are presented in a subsequent section, Service Delivery. This section attempts to answer the question of whether community-based interventions are effective. It covers a range of comprehensive community-based interventions, including case management, home-based services, therapeutic foster care, therapeutic group homes, and crisis services. Although the evidence for the benefits of some of these services is uneven at best, even uncontrolled studies offer a starting point for studying the effectiveness and feasibility of their implementation. Many of the evaluations to date offer a first glimpse into the benefits of these services and the extent to which they may be valuable for further examination. Of these interventions, the most convincing evidence of effectiveness is for home-based services and therapeutic foster care, as discussed below.

There is a special emphasis throughout this section on "children with serious emotional disturbances," as many of these community-based services are targeted to this population of the most serious severely affected children. The term serious emotional disturbance refers to a diagnosed mental health problem that substantially disrupts a child's ability to function socially, academically, and emotionally. It is not a formal DSM-IV diagnosis but rather a term that has been used both within states and at the Federal level to identify a population of children with significant functional impairment due to mental, emotional, and behavioral problems who have a high need for services. The official definition of children with serious emotional disturbance adopted by the Substance Abuse and Mental Health Services Administration is "persons from birth up to age 18 who currently or at any time during the past year had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the DSM-III-R, and that resulted in functional impairment which substantially interferes with or limits the child's role or functioning in family, school, or community activities" (SAMHSA, 1993, p. 29425).[15] The term is used in a variety of Federal statutes in reference to children fitting that description and does not signify any particular diagnosis per se; rather, it is a legal term that triggers a host of mandated services to meet the needs of these children (see Service Delivery section).

Case Management

Case management is an important and widespread component of mental health services, especially for children with serious emotional disturbances. The main purpose of case management is to coordinate the provision of services for individual children and their families who require services from multiple service providers. Case managers take on roles ranging from brokers of services to providers of clinical services.

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[15] This definition is also used with newer diagnostic systems, such as DSM-IV.

There is a considerable amount of variation in models of case management. In one important model, called "wraparound," case managers involve families in a participatory process of developing an individualized plan focusing on individual and family strengths in multiple life domains. Research on wraparound is still in its early stages (Burns & Goldman, 1999).

There have been controlled studies of three programs that used case managers who work individually rather than as part of an interdisciplinary team (discussed later). In one study of the Partner's Project in Oregon, case management was compared with "usual services," which did not include case management (Gratton et al., 1995). The authors found at 1-year followup that children in the Partner's Project scored significantly higher on measures of social competence and had received more individualized, comprehensive services, and a greater degree of service coordination.

The second study compared the outcomes of intensive case management and regular case management for mentally ill homeless children in Seattle (Cauce et al., 1994). The case managers in the intensive condition had lower caseloads, were required to spend more hours supervising the youth, had flexible funds (for clothing, transportation, etc.) at their disposal, spent more hours in consultation with psychologists, and were of higher educational status. After 1 year, the study found that both groups showed substantial yet similar improvement in mental health and social adjustment.

A model known as Children and Youth Intensive Case Management (CYICM) was evaluated in two controlled studies. The program has been described as an Expanded Broker Model, which means that the case manager, in addition to brokering services, is responsible for assessment, planning, linking, and advocating on behalf of the youth and family. Case managers, with caseloads of 10 children, are given $2,000 of flexible funds per child each year to purchase treatment and ancillary services (e.g., transportation and educational aids). In the first study, the authors found that children in the program spent significantly more days in the community between episodes of psychiatric hospitalization and were hospitalized for fewer days than before enrollment (Evans et al., 1994). A subsequent study evaluated a random sample of 199 children enrolled in CYICM (Evans et al., 1996b). Findings at 3-year followup indicated significant behavioral improvements and decreases in unmet medical, recreational, and educational needs compared with findings at enrollment. As in the previous study, children who had been in CYICM for 2 years had spent fewer days in psychiatric hospitals and more days in community settings during the intervals between hospitalizations. This study went further to compare their hospital utilization with that by children not enrolled in the program. Although CYICM clients spent more days in psychiatric hospitals before enrollment, they used inpatient services after enrollment significantly less than did non-enrollees. CYICM clients' hospital admissions declined fivefold after enrollment whereas among non-enrollees the decline in admission rates was less than half that value. This difference translated into a savings of almost $8,000,000 for New York State, where the project took place.

Some research has investigated the effects of extending case management on children with a dual diagnosis of a mental disorder and a substance abuse problem. Within the CYICM program, researchers looked at whether adolescents with mental disorders and substance abuse problems derived comparable benefits from the program as did those without substance abuse problems (Evans et al., 1992). No significant differences were found in the average number of inpatient admissions both before and after enrollment. There was also no significant difference between groups in the average decrease from pre- to postenrollment in the number of days spent in hospitals. These results indicate that case management can be as effective for youth presenting with substance abuse problems as for youth presenting with other psychiatric disorders.

Team Approaches to Case Management

Several studies assessed the value of case management as part of a treatment team. In a randomized trial in North Carolina (Burns et al., 1996), youth served by an interdisciplinary treatment team led by a case manager were compared with a control group of youth served by a treatment team led by their primary clinician in the role of case manager (also called clinician case manager). At 1-year followup, case managers in the experimental group reported spending significantly more time with their clients, as well as significantly more time on the core functions of case management (e.g., outreach; assessment of strengths, needs, and resources; service planning and monitoring; linking, referral, and advocacy; and crisis intervention). The experimental group also remained in the case-managed program longer, spent fewer days in psychiatric hospitals, and received more community-based services and a more comprehensive array of services. Although both groups showed similar clinical and functional improvements, parents of youth in the experimental group reported more satisfaction with the service system. The study concluded that traditional case managers, rather than clinician case managers, provide a more cost-effective method for attaining positive behavioral outcomes and access to mental health services.

Another example of a team approach to case management is the Family Centered Intensive Case Management (FCICM) program. This was originally created as a variation of Child and Youth Intensive Case Management in New York, with the later addition of a wraparound approach. The wraparound approach is based on a belief that the child and family should be placed at the center of an array of coordinated health and mental health, educational, and other social welfare services and resources, which a case manager wraps around the patient and family. In a randomized trial, children were assigned to either FCICM or Family-Based Treatment (Evans et al., 1996a). Family-Based Treatment included training, support, and respite care for foster families but did not include case managers. The findings at 18 months (or at discharge) indicated that children in FCICM had significantly fewer behavioral symptoms and significantly greater improvements in overall functioning than those in Family-Based Treatment. In addition, the average annual cost of FCICM was less than half that of Family-Based Treatment.

The Fostering Individualized Assistance Program (FIAP) is an example of case management provided through a wraparound approach. The effectiveness of this model, which used clinical case managers, was compared with standard foster care in a randomized trial involving 131 children and their families (Clark et al., 1998). The most important duty of the FIAP case managers was to arrange monthly team meetings for the monitoring of individualized service plans. Although both groups showed significant improvement in their behavioral adjustment over a 3½-year period, children in the FIAP group were less likely to change placements, and boys in the group reported better social adjustment and fewer delinquencies. Older youth in the group were more likely to maintain placements in homes of relatives and less likely to run away. Youth in FIAP were also absent from school less often and spent fewer days suspended from school. Overall, youth in the FIAP group showed more improvement than did youth in standard foster care. Multiple uncontrolled studies of case management using a wraparound approach were summarized in a recent monograph focusing on the wraparound process (Burns & Goldman, 1999). Overall, the reviewed studies, although using uncontrolled methods, offer emerging evidence of the potential effectiveness of case management using a wraparound process.

While evidence is limited and many of the positive outcomes focus on service use rather than clinical status, there is some indication that case management is an effective intervention for youth with serious emotional disturbances. Studies in this area are difficult to conduct because of resource limitations and of varying approaches to case management. Agreement on standards for specific case management models is needed in order to proceed with efficient and reliable controlled research in this area. In addition, future research needs to address the issue of cost-effectiveness, as some evidence presented above has shown savings from less utilization of institutional care.

Home-Based Services

This section describes the strong record of effectiveness for home-based services, which provide very intensive services within the homes of children and youth with serious emotional disturbances. A major goal is to prevent an out-of-home placement (i.e., in foster care, residential, or inpatient treatment). Home-based services are usually provided through the child welfare, juvenile justice, and/or mental health systems. They are also referred to as in-home services, family preservation services, family-centered services, family-based services, or intensive family services.

Stroul (1988) identified three major goals of home-based services: to preserve the family's integrity and prevent unnecessary out-of-home placements; to put adolescents and their families in touch with community agencies and individuals, thus creating an outside support system; and to strengthen the family's coping skills and capacity to function effectively in the community after crisis treatment is completed. The specific services provided most often include evaluation, assessment, counseling, skills training, and coordination of services. The historical evolution of home-based services is discussed further under Support and Assistance for Families in Service Delivery.

The evidence for the benefits of home-based services was recently evaluated in a meta-analysis of controlled studies only (Fraser et al., 1997). The analysis referred to home-based services as "family preservation services"; these were sponsored either by the child welfare or juvenile justice systems. For 22 studies the authors analyzed specific measures such as out-of-home placement, family reunification, arrest, incarceration, and hospitalization, with the control group defined as youth receiving "usual" or "routine" services. While a majority of the studies demonstrated marginal gains in effectiveness, other services appeared to be significantly more effective than usual services. The findings are presented below according to their organizational sponsorship by either child welfare or juvenile justice system.

Family Preservation Programs Under the Child Welfare System

Within the child welfare system, particularly effective family reunification programs were the Homebuilders Program in Tacoma, Washington, which was designed to reunify abused and neglected children with their families by providing family-based services (Fraser et al., 1996), and the family reunification programs in Washington State and in Utah (Pecora et al., 1991). Studies suggested that 75 to 90 percent of the children and adolescents who participated in such programs subsequently did not require placement outside the home. The youths' verbal and physical aggression decreased, and cost of services was reduced (Hinckley & Ellis, 1985). The success of these family preservation programs is based on the following: services are delivered in a home and community setting; family members are viewed as colleagues in defining a service plan; back-up services are available 24 hours a day; skills are built according to the individual needs of family members; marital and family interventions are offered; community services are efficiently coordinated; and assistance with basic needs such as food, housing, and clothing is given (Fraser et al., 1997).

Multisystemic Therapy

Multisystemic therapy programs within the juvenile justice system have demonstrated effectiveness. MST is an intensive, short-term, home- and family-focused treatment approach for youth with severe emotional disturbances. MST was originally based on risk factors that were identified in the published literature and was designed for delinquents. MST intervenes directly in the youth's family, peer group, school, and neighborhood by identifying and targeting factors that contribute to the youth's problem behaviors. The main goal of MST is to develop skills in both parents and community organizations affecting the youth that will endure after brief (3 to 4 months) and intensive treatment. MST was constructed around a set of principles that were put into practice and then expanded upon in a manual (Henggeler et al., 1998). Elaborate training, supervision, and monitoring for treatment adherence make this an exemplary approach. Furthermore, publication of an MST manual and the high level of clinical training in MST distinguish this model from other types of family preservation services.

The efficacy of MST has been established in three randomized clinical trials for delinquents within the juvenile justice system. The first of these studies took place in Memphis, Tennessee, and revealed that MST was more effective than usual community services in decreasing adolescent behavioral problems and in improving family relations (Henggeler et al., 1986). The second was conducted in Simpsonville, South Carolina, and compared outcomes for 84 juvenile offenders randomly assigned to either MST or usual services. At 59 weeks after referral, youth who had received MST had fewer arrests and self-reported offenses and had spent an average of 10 fewer weeks incarcerated than did the youth in usual services. In addition, families served by MST reported increased family cohesion and decreased youth aggression in peer relations (Henggeler et al., 1992). In the third study, MST was compared with individual therapy in Columbia, Missouri, and was found to be more effective in ameliorating adjustment problems in individual family members. A 4-year followup of rearrest data indicated that MST was more effective than individual therapy in preventing future criminal behavior, including violent offenses (Borduin et al., 1995). Studies found improved behavior, fewer arrests, and lower costs. These findings encouraged the investigators to test the effectiveness of MST in other organizational settings (e.g., child welfare and mental health), allowing them to target other clinical populations, including youthful sex offenders (Borduin et al., 1990), abused and neglected youth (Brunk et al., 1987), and child psychiatric inpatients (see Inpatient Treatment section). Initial results are promising for youth receiving MST instead of psychiatric hospitalizations (Henggeler et al., 1998). As expected, some adjustments to MST are required to handle children who are dangerous to themselves and who do not respond as quickly to treatment as the delinquent youth in previous studies. The efficacy of MST was demonstrated in real-world settings but only by one group of investigators; thus, the results need to be reproduced by others and future effectiveness research needs to determine whether the same benefits can be demonstrated with less support from experts.

Therapeutic Foster Care

Therapeutic foster care is considered the least restrictive form of out-of-home therapeutic placement for children with severe emotional disorders. Care is delivered in private homes with specially trained foster parents. The combination of family-based care with specialized treatment interventions creates "a therapeutic environment in the context of a nurturant family home" (Stroul & Friedman, 1988). These programs, which are often funded jointly by child welfare and mental health agencies, are responsible for arranging for foster parent training and oversight. Although the research base is modest compared with other widely used interventions, some studies have reported positive outcomes, mostly related to behavioral improvements and movement to even less restrictive living environments, such as traditional foster care or in-home placement.

While therapeutic foster care programs vary considerably, they have some features in common. Children are placed with foster parents who are trained to work with children with special needs. Usually, each foster home takes one child at a time, and caseloads of supervisors in agencies overseeing the program remain small. In addition, therapeutic foster parents are given a higher stipend than that given to traditional foster parents, and they receive extensive preservice training and in-service supervision and support. Frequent contact between case managers or care coordinators and the treatment family is expected, and additional resources and traditional mental health services may be provided as needed.

Therapeutic foster care programs are inexpensive to start (few requirements for facilities or salaried staff) and have lower costs than more restrictive programs. In

Ontario, a study found that therapeutic foster care cost half that of residential treatment center placement for the same period of time (Rubenstein et al., 1978).

There have been four efficacy studies, each with randomized, controlled designs. In the first study, 20 youths who had been previously hospitalized were assigned to either therapeutic foster care or other out-of-hospital settings, such as residential treatment centers or homes of relatives. The youths in therapeutic foster care showed more improvements in behavior and lower rates of reinstitutionalization, and the costs were lower than those in other settings (Chamberlain & Reid, 1991). In another study, which concentrated on youths with histories of chronic delinquency, those in therapeutic foster care were incarcerated less frequently and for fewer days per episode than youths in other residential placements. Thus, at 2-year followup, 44 percent fewer children in therapeutic foster care were incarcerated (Chamberlain & Weinrott, 1990). In a third study, outcomes for children in therapeutic foster care were compared with those of children in standard foster care. Children in therapeutic foster care were less likely during a 2-year study to run away or to be incarcerated and showed greater emotional and behavioral adjustment (Clark et al., 1994). In the most recent study, therapeutic foster care was compared with group care: children receiving the former showed significantly fewer criminal referrals, returned to live with relatives more often, ran away less often, and were confined to detention or training schools less often (Chamberlain & Reid, 1998).

All four studies of treatment effectiveness showed that youths in therapeutic foster care made significant improvements in adjustment, self-esteem, sense of identity, and aggressive behavior. In addition, gains were sustained for some time after leaving the therapeutic foster home (Bogart, 1988; Hawkins et al., 1989; Chamberlain & Reid, 1991).

There are also promising indications from uncontrolled studies. Looking at 18 reports from 12 therapeutic foster care programs across the country, Kutash and Rivera (1996) concluded that between about 60 and 90 percent of youth treated in therapeutic foster homes are discharged to less restrictive settings. Three programs also reported followup data, indicating that about 70 percent of youth treated in therapeutic foster homes remained in less restrictive settings for a substantial amount of time after treatment.

It is clear from these studies that therapeutic foster care produces better outcomes at lower costs than more restrictive types of placement. Furthermore, with the fairly recent development of standards for therapeutic foster care, as well as a standards review instrument (Foster Family-Based Treatment Association, 1995), services can be monitored for quality and fidelity to the therapeutic approach, making it easier to ascertain if the approach taken produces the favorable outcomes.

Therapeutic Group Homes

For adolescents with serious emotional disturbances the therapeutic group home provides an environment conducive to learning social and psychological skills. This intervention is provided by specially trained staff in homes located in the community, where local schools can be attended. Each home typically serves 5 to 10 clients and provides an array of therapeutic interventions. Although the types and combinations of treatment vary, individual psychotherapy, group therapy, and behavior modification are usually included.

There are two major models of therapeutic group homes. The first is the teaching family model, developed at the University of Kansas, then moved to Boys Town in Omaha, Nebraska (Phillips et al., 1974). The second is the Charley model, developed at the Menninger Clinic. Both models use their staff as the key agents for change in the disturbed youth; selection and training of the staff are emphasized. Both models employ couples who live at the homes 24 hours a day. The teaching family model emphasizes structured behavioral interventions through teaching new skills and positively reinforcing improved behavior. Other group homes use individual psychotherapy and group interaction.

There is a dearth of research on the effectiveness of therapeutic group home programs targeted toward emotionally disturbed adolescents. These homes have been developed primarily for children under the care of juvenile justice or social welfare. A dissertation (Roose, 1987) studied the outcomes of 20 adolescents treated in a group home. Adolescents with severe character pathology or major psychiatric disorders were not admitted. Twenty group home adolescents were compared with 20 untreated adolescents. At an 18-month followup, 90 percent of the treated group had fair or good functioning, defined by improved relationships with parents, peers, and fellow workers. Only 45 percent of the untreated group achieved similar functioning. The treated group experienced a significant decrease in psychopathology, while the untreated group did not.

Therapeutic group homes were compared with therapeutic foster care in two studies. The first study found equivalent gains for youth in the two interventions, but group home placement was twice as costly as therapeutic foster care (Rubenstein et al., 1978). A second study, a randomized clinical trial, compared the outcomes for 79 males with histories of juvenile delinquency placed in either group homes or therapeutic foster homes (Chamberlain & Reid, 1998). The boys treated in therapeutic foster homes had significantly fewer criminal referrals and returned more often to live with relatives, suggesting this to be a more effective intervention. The implication of these studies is that if therapeutic foster care is available, and if the foster parents are willing to take youth with serious behavioral problems, therapeutic foster care may be a better treatment choice for youth who previously would have been placed in group homes.

Existing research suggests that therapeutic group home programs produce positive gains in adolescents while they are in the home, but the limited research available reveals that these changes are seldom maintained after discharge (Kirigin et al., 1982). The conclusion may be similar to that for residential treatment center placement: long-term outcomes appear to be related to the extent of services and support after discharge. Adolescents who have been placed in therapeutic group homes because of mental disorders frequently have histories of multiple prior placements (particularly in foster homes), a situation that is associated with a poor prognosis. Thus, future programs would benefit from assessing alternative strategies for treatment after discharge from group homes.

Crisis Services

Crisis services are used in emergency situations either to furnish immediate and sufficient care or to serve as a transition to longer term care within the mental health system. These services are extremely important because many youth enter the mental health service system at a point of crisis. Crisis services include three basic components: (1) evaluation and assessment, (2) crisis intervention and stabilization, and (3) followup planning. The goals of crisis services include intervening immediately, providing brief and intensive treatment, involving families in treatment, linking clients and families with other community support services, and averting visits to the emergency department or hospitalization by stabilizing the crisis situation in the most normal setting for the adolescent. Crisis services include telephone hotlines, crisis group homes, walk-in crisis intervention services, runaway shelters, mobile crisis teams, and therapeutic foster homes when used for short-term crisis placements.

Crisis programs are small in order to facilitate close relationships among the staff, child, and family. Crisis staff are required to have skills and experience in the areas of assessment, emergency treatment, and family support. Short-term services are provided, with the staff meeting more frequently with the client at the outset of the crisis. A typical treatment plan consists of 10 sessions over a period of 4 to 6 weeks. Crisis services usually are available 24 hours a day, 7 days a week (Goldman, 1988).

Research on crisis services consists exclusively of uncontrolled studies. Kutash and Rivera (1996) reviewed 12 studies with pre-post[16] designs. Positive behavioral and adjustment outcomes for youth presenting to crisis programs and emergency departments across the country were reported in all of the studies. Most programs also demonstrated the capacity to prevent institutionalization.

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[16] Pre-post design: a research design in which a measure is compared on the same individual research subjects before and after an intervention.

The most recent studies examine three different models: a mobile crisis team, short-term residential services, and intensive in-home service. The first study examined the Youth Emergency Services (YES) program in New York. This program included a mobile crisis team that sent clinicians directly to the scene of the crisis. The data showed that YES prevented emergency department visits and out-of-home placements (Shulman & Athey, 1993).

A second crisis program, in Suffolk County, New York, involved short-term residential services. In a study of 100 children served by the program over a 2-year period, more than 80 percent were discharged in less than 15 days. Most were diverted from inpatient hospitalization, and inpatient admissions to the state children's psychiatric center for Suffolk County were reduced by 20 percent after the program was established (Schweitzer & Dubey, 1994).

In the third study, records were analyzed from a large sample of youth (nearly 700) presenting to the Home Based Crisis Intervention (HBCI) program in New York over a 4-year period. Youth received short-term, intensive, in-home emergency services. After an average service episode of 36 days, 95 percent of the youth were referred to, or enrolled in, other services (Boothroyd et al., 1995). The HBCI program was established at eight locations across the State of New York. Overall, programs with more access to community resources reported shorter average lengths of services.

Although crisis and emergency services represent a promising intervention, the research done so far only includes uncontrolled studies, limiting the conclusions that can be drawn. Kutash and Rivera (1996) recommend additional effectiveness research using controlled study designs and comparing differences between the various types of crisis services. Finally, there remains a need for investigation of cost-effectiveness as well as an exploration of the integration of crisis services into systems of care.

Service Delivery

The focus of this section is on service systems—their origins, nature, and financing and also their effectiveness, delivery, and utilization—rather than on individual interventions and treatments, which were covered in previous sections of this chapter.

About 20 years ago it became clear that children and families were failing to receive adequate care from the public sector, whose services were fragmented, inadequate, and overreliant on institutional care. As a result, the emphasis of service delivery has shifted to systems of care that are designed to provide culturally competent, coordinated services; community-based services; new financing arrangements in the private and public sectors; family participation in decisionmaking about care for their children; and individualized care drawing on treatment and social supports called wraparound services, described above. Thus, there has been progress in transforming the nature of service delivery and its financing, but the central question of the effectiveness of systems of care has not yet been resolved.

At the outset, it is important to note that while systems of care are designed to provide the appropriate level of services for all children, it is children with serious emotional disturbances, particularly children who are involved in multiple service sectors, who are likely to benefit the most. There are approximately 6 million to 9 million children and adolescents in the United States with serious emotional disturbances (Friedman et al., 1996a; Lavigne et al., 1996), accounting for 9 to 13 percent of all children (Friedman et al., 1996a; Friedman et al., 1998).

The system for delivering mental health services to children and their families is complex, sometimes to the point of inscrutability—a patchwork of providers, interventions, and payers. Much of the complexity stems from the multiple pathways into treatment and the multiple funding streams for services. However, once care has begun, the interventions and settings themselves are generally the same as those covered in previous sections of this chapter.

Service Utilization

This section presents research findings about the utilization of mental health services by children and adolescents. The foremost finding is that most children in need of mental health services do not get them. Another finding refutes the common perception that children who do not need specialty mental health services are more likely to receive such services than those who really do need them. This section also discusses children's high dropout rates from treatment and the significance of this problem for children of different cultural backgrounds.

Utilization in Relation to Need

The conclusion that a high proportion of young people with a diagnosable mental disorder do not receive any mental health services at all (Burns et al., 1995; Leaf et al., 1996) reinforces an earlier report by the U.S. Office of Technology Assessment (1986), which indicated that approximately 70 percent of children and adolescents in need of treatment do not receive mental health services. Only one in five children with a serious emotional disturbance used mental health specialty services, although twice as many such children received some form of mental health intervention (Burns et al., 1995). Thus, about 75 to 80 percent fail to receive specialty services, and the majority of these children fail to receive any services at all, as reported by their families. The most likely reasons for underutilization relate to the perceptions that treatments are not relevant or are too demanding or that stigma is associated with mental health services; the reluctance of parents and children to seek treatment; dissatisfaction with services; and the cost of treatment (Pavuluri et al., 1996; Kazdin et al., 1997).

Studies do, however, demonstrate a clear and strong relationship between use of services and presence of a diagnosis and/or presence of impaired functioning. In the study by Leaf and colleagues (1996), young people with both a diagnosis and impaired functioning were 6.8 times more likely to see a specialist than were those with no diagnosis and a higher level of functioning.

The study by Burns and colleagues also showed where children were receiving treatment. Of those who received services and had both a diagnosis and impaired functioning, about 40 percent received services in the specialty mental health sector, about 70 percent received services from the schools, about 11 percent from the health sector, about 16 percent from the child welfare sector, and about 4 percent from the juvenile justice sector. For nearly half the children with serious emotional disturbances who received services, the public school system was the sole provider (Burns et al., 1995). After reviewing these findings and the findings from other studies, Hoagwood and Erwin (1997) also concluded that schools were the primary providers of mental health services for children.

Early Termination of Treatment

Among children and adolescents who begin treatment, the dropout rate is high, although estimates vary considerably. According to Kazdin and colleagues (1997), 40 to 60 percent of families who begin treatment terminate it prematurely. Armbruster and Fallon (1994) found that the great majority of children who enter outpatient treatment attend for only one or two sessions. One of the explanations for the high dropout rate and for failure to keep the first appointment is that referrals are often made not by children and adolescents or their families, but by schools, courts, or other agencies. Most of the research on dropping out has focused exclusively on examining demographic or diagnostic correlates of dropping out, and few researchers have directly asked the children or their parents about their reasons for discontinuing treatment.

There are a number of effective interventions to reduce dropout from treatment and to increase enrollment and retention (Szapocznik et al., 1988; McKay et al., 1996; Santisteban et al., 1996). Offering services in the schools improves treatment access (Catron & Weiss, 1994). A variety of case management approaches can also improve engagement of low-income families in the treatment of their children (Burns et al., 1996; Koroloff et al., 1996a; Lambert & Guthrie, 1996).

Poverty and Utilization

Poverty status has been associated with both dropping out of services and shorter lengths of treatment (Hoberman, 1992). This relationship between underutilization of mental health services and poverty is especially significant for minority children and families. Youths receiving community mental health services supported by public agencies tend to be male, poor, and referred by social agencies (Canino et al., 1986; Costello & Janiszewski, 1990). Furthermore, investigators have found this pattern particularly true for African Americans as compared with Caucasians. Hoberman (1992) has found that 90 percent of African American youths entering the mental health system live in poverty.

Culture and Utilization

Although it is clear that an insufficient number of children receive mental health services, it is not clear whether utilization of services varies by race or ethnicity. The majority of studies have found that African Americans tend to use some mental health services, particularly inpatient care, more than would be expected from their proportion in the population. However, research findings are conflicting, probably due to divergent methodological approaches (Attkisson et al., 1995; McCabe et al., 1998; Quinn & Epstein, 1998). Furthermore, as Attkisson and colleagues (1995) point out, consistent with the study by McCabe and colleagues (1998), it is difficult to interpret these findings in the absence of epidemiologic data on the prevalence of a mental disorder in different racial and ethnic groups. Recent reviews of epidemiological findings concluded that present data are inadequate to determine the relationship between race or ethnicity and prevalence of a mental disorder (Friedman et al., 1996b; Roberts et al., 1998).

The task of understanding treatment patterns is made even more difficult because there are racial and ethnic differences in family preferences and family-initiated patterns of help-seeking (see also Culturally Appropriate Social Support Services). For example, parents from various cultural backgrounds have been found to differ in the degree to which they identify child behavioral and emotional problems as disturbed (Weisz & Weiss, 1991). Differences also have been found across cultural groups in their beliefs about whether these child problems are likely to improve in the absence of professional support. Weisz and Weiss (1991) have also identified cultural differences in the power of various children's behavioral and emotional problems to motivate a parent's search for professional help.

Differences also arise indirectly from the multiplicity of service systems with authority and responsibility for protecting the well-being of children. These systems have different criteria for initiating treatment and different patterns of utilization. African American children and youth are considerably more likely than those of other ethnic groups to enter the child welfare system (National Research Council, 1993). Their greater chances of having parents compelled to surrender them or of suffering abuse or neglect lead them in greater numbers to be referred to child welfare authorities, to be placed out-of-home, and to be involved with the child welfare system longer. Studies in one California county have found that African American youths are overrepresented in arrests, detention, and incarceration in the juvenile justice system, and in the schools they are overrepresented in educational classes for the severely emotionally disturbed. Hispanic/Latino children and youths are no more likely than whites to come under supervision of the child welfare system but, once involved, remain longer. They are also more likely than whites to be detained in juvenile justice facilities (McCabe et al., 1998).

As a group, Hispanic/Latino and African American children more often leave mental health services prematurely than do Caucasian children (Sue et al., 1991; Bui & Takeuchi, 1992; Takeuchi et al., 1993; Viale-Val et al., 1984). Many factors contribute to premature termination, such as insensitivity of mental health providers to the culture of children and families (Woodward et al., 1992). In general, even after demonstrated success with middle-class Caucasians, mental health treatments should not be applied without culturally appropriate modification to people from other cultures and races (Rosado & Elias, 1993).

Specialized programs and supports linked with the culture of the community being served have been found to be successful in promoting favorable patterns of service utilization for all ages (Snowden & Hu, 1997). It is becoming clear that the children and families served by mental health programs designed to be linked to community cultures are less likely to drop out of treatment compared with similar families in mainstream programs (Takeuchi et al., 1995). For example, Asian American children at an Asian community- or culture-focused program were found to use more services, drop out less often, and improve more than did Asian American children at mainstream programs (Yeh et al., 1994).

In summarizing the relationship between race and ethnicity, need for service, and use of service, Isaacs-Shockley and colleagues (1996) raised the concern that minority children are less likely to receive the care they need than nonminority children—a concern that should energize advocacy for the development of systems of care tailored to the needs of distinct cultures (Cross et al., 1989; Hernandez & Isaacs, 1998).

Service Systems and Financing

In the past, mental health services paid for by the private sector were viewed as separate entities from those funded by the public sector, particularly since the public sector only paid for services that it itself delivered. As this section explains below, the distinction between public and private sectors has been blurred by the advent of publicly supported payment systems such as Medicaid and grants of public funds to private organizations and providers. Now in the public sector, services are paid for with governmental resources but delivered either by public or private organizations in institutional or community-based settings.

Private Sector

The private sector uses a health insurance model that reimburses for acute medical problems. Under this traditional model, mental health coverage usually entails outpatient counseling, medication treatments, and short-term inpatient hospitalization. Under more generous insurance plans, including some managed care plans, intermediate services, such as crisis respite and day hospitalization (also called partial hospitalization or day treatment), are becoming more popular although more traditional insurance plans continue to restrict their use. The drive to reduce the cost of inpatient care is sparking an expansion in the range of services supported by the private sector.

When children and adolescents have complex and long-term mental health problems, required services are not usually covered by private sector insurance plans. Families must either pay for the services themselves or obtain the services through the public sector. In many states, parents are forced to give up custody of their children to the state child welfare system in order to obtain needed residential services (Cohen et al., 1991). This unfortunate choice results from a limited supply of public sector services and special requirements for gaining access to them.

Over the past decade, managed care has become a major payer for private health care. Managed care provision of mental health services emerged partially in response to the overutilization of costly inpatient hospitalization by adolescents in the 1980s (Lourie et al., 1996). The purpose of managed care has been to control spiraling mental health service costs, mostly by limiting hospital stays and rigorously managing outpatient service usage (Stroul et al., 1998). Managed care can offer advantages in terms of cost-effective services to meet the needs of children with flexible benefits. It may also lead to denial of needed treatment. While its potential negative effect on the efficacy of mental health care delivered under its aegis is a hotly debated issue, for the most part managed care furnishes the same traditional services available under fee-for-service insurance. The drive for efficiency, however, has led to the introduction of intermediate services designed to divert children from hospitalization. Managed care has shortened hospital stays and increased the use of short-term therapy models (Eisen et al., 1995; Merrick, 1998). Managed care also has lowered reimbursements for services provided by both individual professionals and institutions. This has been accompanied by the construction of provider networks, under which professionals and institutions agree to accept lower than customary fees as a tradeoff for access to patients in the network.

Public Sector

Mental health services provided by the public sector are more wide-ranging than those supported by the private sector, and the types of payers are more diverse. Some public agencies, such as Medicaid and state and local departments of mental health, are mandated to support mental health services. Others provide mental health services to satisfy mandates in special education, juvenile justice, and child welfare, among others.

Medicaid is a major source of funding for mental health and related support services. For the most part, Medicaid has supported the traditional mix of outpatient and inpatient services. However, unlike private sector insurance, Medicaid also funds long-term services for those children who need more intensive or restrictive services, often through hospitalizations and residential treatments. Some states cover in-home services, school-based services, and case management through a variety of Medicaid options. Medicaid also supports the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program.

Trapped between the private and public sectors is a group of uninsured individuals and families who do not qualify for the public sector programs, cannot afford to pay for services themselves, and have no access to private health insurance. The American Academy of Pediatrics estimates that in 1999 there will be 11 million uninsured children, about 3 million of whom do not qualify for existing public programs (American Academy of Pediatrics website www.aap.org). State and local mental health authorities fund some mental health services for these children, often offered through the same community mental health centers that are funded by Medicaid. Mental health departments in some jurisdictions also fund a broader array of mental health services than the traditional acute service package. These "intermediate" services include intensive case management with and without individualized wraparound provisions, early intervention programs, crisis stabilization, in-home therapy, and day programs. Since there has never been a mandate to states to provide mental health services to children and adolescents, the state or local support for such services has been variable. Thus, one might find a well-supported, innovative array of mental health services for children in one state or community, and almost no services in the next. The new State Child Health Insurance Program (CHIP) is an attempt by Congress to address the health care needs of low-income, uninsured children. States have great flexibility in their approach to coverage, and it remains to be seen how they will deal with mental health services.

States and communities have sweeping mandates to serve children and adolescents in schools and under child welfare and juvenile service auspices. Many of these state and community programs, however, lack the expertise to recognize, refer, or treat mental health problems that trigger mandated services. When they do recognize problems, some of the needed mental health services are paid for by Medicaid, by the federal Maternal and Child Block Grant, or by a state or local mental health authority; often, however, they are not. Under these circumstances, the school, welfare, or juvenile justice agency ends up paying the bill for the mental health services.

Under the Federal special education law, the Individuals with Disabilities Education Act[17] (IDEA; see also New Roles for Families in Systems of Care), school systems are mandated to provide special education services to children and adolescents whose disabilities interfere with their education. When these disabilities take the form of serious emotional or behavioral disturbances, school systems are required to respond through assessment, counseling, behavior management, and special classes or schools. When school systems lack sufficient capacity to meet such needs directly, school funds are used to send children and youths to specialized private day schools or to long-term residential schools, even if such schools are out of the child's state or community. In this way, school systems support an extensive array of mental health services in the public and private sectors.

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[17] Public Law 94-142; Public Law 101-476; Public Law 105-17

Preschool children with developmental and emotional disabilities are covered by some state and local legislation. Services for them also are mandated under IDEA. Whereas some states coordinate this education-based mandate through school systems, others administer the preschool programs through mental health or developmental disability agencies, an interagency coordinating body, or other state agency.

Child welfare agencies in states and communities also have powerful mandates to protect children and to ensure that they receive the services they need, including mental health services. Child welfare agencies primarily serve poor children who are separated from their parents because they are orphaned, abandoned, abused, or neglected. Although many mental health services are provided either under Medicaid or through state and locally supported community mental health centers, many are not and are paid for directly by child welfare agencies. This happens most often when children and adolescents have severe, complicated conditions. As with education agencies, when funding is not available through Medicaid or other mental health funds, child welfare agencies directly pay for group home care, therapeutic foster care, or residential treatment.

The same is true for juvenile justice agencies, which have strong mandates to protect children and the public. Many children and adolescents in the juvenile justice system have serious mental health problems. Beyond the more traditional "training schools" and "detention centers," run by state and local juvenile authorities, respectively, these agencies also purchase care from the same group home, therapeutic foster care, and residential providers as do child welfare agencies.

Children Served by the Public Sector

Children needing services are identified under the auspices of five distinct types of service sectors: schools, juvenile justice, child welfare, general health, and mental health agencies. These agencies are mostly publicly supported, each with different mandates to serve various groups and to provide somewhat varied levels of services. Many of these agencies arose historically for another purpose, only to recognize later that mental disorders cause, contribute to, or are effects of the problem being addressed. In the past, these sectors operated somewhat autonomously, with little ongoing interaction. Catalyzed by the NMHA's Invisible Children's Project (NMHA, 1987, 1993), the combined impetus of Federal policies and managed care more recently has begun to forge their integration.

Two recent review articles examined the characteristics of children served in public systems. Based on an appraisal of six prior studies, it was concluded that, in addition to emotional and behavioral functioning, these young people have problems in life domains such as intellectual and educational performance and social and adaptive behavior (Friedman et al., 1996b). Frequently, such children and their families have contact not only with the mental health system, but also with special education, child welfare, and juvenile justice (Landrum et al., 1995; Duchnowski et al., 1998; Greenbaum et al., 1998; Quinn & Epstein, 1998).

It is estimated that in a 1-year period more than 700,000 children nationwide are in out-of-home placements, mostly under the supervision of either the child welfare or to some extent the juvenile justice system (Glisson, 1996). Also, during the 1996–1997 school year more than 400,000 emotionally disturbed children and youths between the ages of 6 and 21 were served in the public schools nationwide (U.S. Department of Education, 1997). This is just under 1 percent of the school enrollment for ages 6 to 17, and 8.5 percent of all children with disabilities receiving any kind of special education service (Oswald & Coutinho, 1995; U.S. Department of Education, 1997). These figures and percentages have remained relatively constant since national data were first collected about 20 years ago, although there are great variations between states. For example, in 1992–1993, 0.4 percent of school-enrolled children in Mississippi were identified as having a serious emotional disturbance compared with 2.08 percent in Connecticut (Coker et al., 1998).

In addition to children with a serious emotional disturbance served by the special education system, children served by child welfare and juvenile justice systems also have need for mental health services (Friedman & Kutash, 1986; Cohen et al., 1990; Greenbaum et al., 1991, 1998; Otto et al., 1992; Glisson, 1996; Claussen et al., 1998), because they are much more likely to have emotional and behavioral disorders than is the general population (Duchnowski et al., 1998; Quinn & Epstein, 1998). Thus, the emphasis on interagency community-based systems of care is warranted and essential (see Integrated System Model).

Managed Care in the Public Sector

Since 1992, managed care has begun to penetrate the public sector (Essock & Goldman, 1995). The prime impetus for this has been an attempt to control the costs of Medicaid, in both the general health and mental health arenas. Since Medicaid appears, on the surface, to be similar to a private health insurance plan, administrators of state Medicaid programs have recently implemented managed care approaches and structures to reduce health care costs. However, Medicaid populations tend to have a higher prevalence of children with serious emotional disturbance than that seen in privately insured populations. Those children generally need longer-term care (Friedman et al., 1996b; Broskowski & Harshbarger, 1998). Managed care strategies, which developed in the private sector, are geared toward a relatively low utilization of mental health services by a population whose mental health needs tend to be short term and acute in nature. As a result, the kinds of cost-cutting measures used by managed care organizations, such as reduction of hospital days and encouragement of short-term outpatient therapies, have not worked as well in the public sector with seriously emotionally disturbed children as they have in the private sector (Stroul et al., 1998).

Advocates express concern that the restrictions of public managed care on mental health services shift costs of diagnosis and treatment to other agencies, a process known as cost-shifting. Under public managed care, hospitalization for mental disorders is being substantially cut, with youths being discharged from the hospital before adequate personal and/or community safety plans can be instituted. Child welfare and juvenile justice agencies have been compelled to create and pay for services to support those children who are no longer kept in hospitals. Thus, while Medicaid's mental health costs may be decreasing in such cases, there may be a substantial cost increase to the other agencies involved, resulting in little if any overall cost saving (Stroul et al., 1998).

Similarly, management of only the Medicaid portion of a complex funding system that includes Medicaid, mental health, special education, child welfare, and juvenile justice funds not only creates the cost-shifting described above, but also underestimates the need to manage the funds spent by all agencies. Demonstration programs of managed care strategies for children and adolescents with severe emotional disturbances have included the creation of an interagency funding pool, shared by all affected agencies, to meet the full range of needs of this population. Under the demonstration program, the funds in such a pool are capitated[18] to ensure that the most appropriate services are purchased, regardless of which agency's mandate they come under. In this way, long-term, complex care can be offered in an efficient way that reduces costs for all of the involved child and youth agencies.

An excellent example of an approach in a managed care setting is "Wraparound Milwaukee," one of the Center for Mental Health Services' Comprehensive Community Mental Health Services for Children and Their Families Programs (Stroul et al., 1998; Goldman & Faw, 1998). Wraparound Milwaukee, a coordinated system of community-based care and resources for families of children with severe emotional, behavioral, and mental health problems, is operated by the Children and Adolescent Services Branch of the Milwaukee County Mental Health Division. The features of this care management model are a provider network that furnishes an array of mental health and child welfare services; an individualized plan of care; a care coordinator management system to ensure that services are coordinated, monitored, and evaluated; a Mobile Urgent Treatment Team to provide crisis intervention services; a managed care approach including preauthorization of services and service monitoring; and a reinvestment strategy in which dollars saved from decreased use of inpatient or residential care are invested in increased service capacity.

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[18] Capitation: a fixed sum per individual per month

Since its inception in 1994, one of the goals of the program has been to blend funding streams. Wraparound Milwaukee operates as a behavioral health care "carve-out"[19] that blends funds from a monthly capitation rate from Medicaid, a case rate from county child welfare and juvenile justice funds, and a Center for Mental Health Services child mental health services grant. The Wraparound Milwaukee capitated rate of approximately $4,300 covers all mental health and substance abuse services, including inpatient hospitalization. Additional funds from child welfare and/or juvenile justice are used for children with serious emotional disturbances in the child welfare and juvenile justice systems in Milwaukee County to cover residential treatment, foster care, group home and shelter care costs, and nontraditional mental health community services (e.g., mentors, job coaches, after-school programs). Wraparound Milwaukee is at "full risk" for all services costs, meaning it is responsible for charges in excess of the capitated rate. The average monthly costs, including administrative costs, are $3,400 per child. Medicaid-eligible children constituted 80 percent of the population served by the program in 1998.

Culturally Appropriate Social Support Services

One of the fundamental requirements of culturally appropriate services is for mental health providers to identify and then to work in concert with natural support systems within the diverse communities they serve (Greenbaum, 1998). (Background information on cultural diversity and culturally competent services is provided in Chapter 2.) If they are culturally appropriate, services can transcend mental health's focus on the "identified client" to embrace the community, cultural, and family context of a client (Szapocznik & Kurtines, 1993; Hernandez et al., 1998). According to Greenbaum (1998), considering a client's context is important because people who live close to each other frequently have developed ways of coping with similar personal problems. Becoming aware of these natural systems and adapting formal services to be congruent with them are ways to make services more accessible and useful to diverse populations.

Community- and neighborhood-based social networks act as important resources for easing emotional stress and for facilitating the process of seeking professional help (Saunders, 1996). Often natural social supports ameliorate emotional distress and have been found to reduce the need for formal mental health treatment (Linn & McGranahan, 1980; Birkel & Reppucci, 1983; Cohen & Wills, 1985). According to Saunders (1996), obtaining social support is not a single event but rather an ongoing process. In general, people use their neighborhood and familial supports many times before they decide they have a problem and determine what type of help they will seek (Rew et al., 1997). A key to the success of mental health programs is how well they use and are connected with established, accepted, credible community supports. The more this is the case, the less likely families view such help as threatening and as carrying stigma; this is particularly true for families who are members of racial and ethnic minority groups (Bentelspacher et al., 1994).

Minority parents are more likely than nonminority parents to seek input regarding their children from family and community contacts (Briones et al., 1990; Hoberman, 1992). In a study by McMiller and Weisz (1996), two-thirds of the parents of minority children did not seek help from professionals and agencies as their first choice. For example, in Hispanic/Latino families, important decisions related to health and mental health are often made by the entire family network rather than by individuals (Council of Scientific Affairs, 1991). According to Ruiz (1993), health care settings that are not modified to work with

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[19] Carve-out: separation of funding for mental health services and their management from those of general health.

Hispanic/Latino family networks find that their clients do not comply with medical advice; as a result, their health status can be compromised.

In sum, mental health programs attempting to serve diverse populations must incorporate an understanding of culture, traditions, beliefs, and culture-specific family interactions into their design (Dasen et al., 1988) and form working partnerships with communities in order to become successful (Kretzman & McKnight, 1993). Ultimately, the solution offered by professionals and the process of problem resolution or treatment should be consistent with, or at least tolerable to, the natural supportive environments that reflect clients' values and help-seeking behaviors (Lee, 1996).

Such partnerships sometimes fail, however, because they concentrate on neighborhood and community problems. According to Kretzman and McKnight (1993), this approach often reinforces the negative stereotypes of violent, drug- and gang-ridden, and poverty-stricken communities. A more effective alternative approach to working with communities is to focus on community strengths (Kretzman & McKnight, 1993). This approach works best when community residents themselves are interested in participating in the partnership. Mental health providers who approach minority communities in a paternalistic manner fail to engage residents and fail to recognize whether the community wants their assistance (Gutierrez-Mayka & Contreras-Neira, 1998). Service providers who attend to the wishes of community residents are more likely to be respectful in their delivery of services, a respect that is a prerequisite to cultural responsiveness and competence in service planning and delivery to diverse communities (Gutierrez-Mayka & Contreras-Neira, 1998).

Support and Assistance for Families

Any parent or guardian of a child with an emotional or behavioral disorder can testify to the challenging, sometimes overwhelming, task of caring for and raising such a child. In the past, support from public agencies has been inadequate and disjointed. Compounding the problem was the view that parents were partly, if not completely, to blame for their child's condition (Friesen & Stephens, 1998). In 1982, a particularly incisive description of the problems faced by families raising children with emotional or behavioral disorders was published. It concluded that parents received little assistance in finding services for their children and were either ignored or coerced by public agencies; respite and support services to relieve the stress on parents were unavailable; parents with children needing residential care were compelled to give up custody to get them placed; and few advocacy efforts were aimed at relieving their problems (Knitzer, 1982).

Over the past two decades, however, recognition and response to the plight of families have become increasingly widespread. The role of families has been redefined as that of a partner in care. Furthermore, there was growing awareness of the difficulties families faced because services are provided by so many different public sources. In addition to problems with coordination, parents and caregivers encountered conflicting requirements, different atmospheres and expectations, and contradictory messages from system to system, office to office, and provider to provider (Knitzer, 1982). Although some agencies began to provide families with training, information, education, and financial assistance, there was often a gap between what families needed and what agencies provided. Also, service agencies themselves began to recognize that putting children into institutions may not have served the child, the family, or the state and that keeping a child with his or her family could reduce the ever-growing costs of institutionalization (Stroul, 1993a, 1993b). Emerging awareness of these foregoing problems galvanized advocacy for a better way to care for children with emotional and behavioral disorders. Reforms were instituted in many Federal programs, as discussed later in this section.

According to Knitzer and colleagues (1993), family participation promotes four changes in the way children are served: increased focus on families; provision of services in natural settings; greater cultural sensitivity; and a community-based system of care. Research is accumulating that family participation improves the process of delivering services and their outcomes. For example, Koren and coworkers (1997) found that, for children with serious mental health problems, the more the family participates in planning services, the better family members feel their children's needs are being met; participation in service planning also helps service coordination. Curtis and Singh (1996) and Thompson and colleagues (1997) also found that family involvement in services was a determinant of the level of parental empowerment, that is, how much control parents felt they had over their children's treatment.

New Roles for Families in Systems of Care

Over the past two decades, the Federal government established a series of initiatives to support families. Parents were given progressively greater roles as decisionmakers with the passage of the Education of the Handicapped Act in 1975 and its successor legislation, the Individuals with Disabilities Education Acts of 1991 and 1997. For simplicity, these pieces of legislation are collectively referred to hereinafter as the IDEA Act. This act requires parent involvement in decisions about educating children with disabilities. It guarantees that all children with disabilities receive free and appropriate public education. It also provides funding assistance to states for implementation.

A novel approach taken by some community-level systems of care to encouraging involvement of families is to train and hire family members into a wide range of well-paying, career-ladder jobs as outreach workers, service coordinators (sometimes called case managers), and direct support services providers. These positions are critical to achieving major program goals because they make it possible for children and families to remain together and to participate in the more clinical components of their service plan. Family members are also employed as supervisors of services, involved in hiring staff, providing them with orientation and on-the-job training (e.g., of case managers), overseeing their work, and evaluating their performance. They also participate in research.

Beginning in 1989, the Child and Adolescent Service System Program, a component of the Center for Mental Health Services, began providing some support for statewide family organizations through a series of funding and technical assistance mechanisms (Koroloff et al., 1991; Briggs et al., 1994; also see Integrated System Model). Such organizations were funded to develop statewide networks of information and support for families, to coordinate with other organizations that shared common goals, and to promote needed changes. Currently, Federal funding for 22 statewide family organizations is provided through the Child and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. Support and technical assistance to community-level family organizations are also provided by the Federation of Families for Children's Mental Health, the National Alliance for the Mentally Ill, and other family-run consumer organizations.

Family Support

Family support is defined here as the assistance given to families to cope with the extra stresses that accompany caring for a child with emotional disabilities. In addition to the stress of raising a child with an emotional disability, families often face other difficulties such as poverty, joblessness, substance abuse, and victimization. Family support often helps keep families together by assisting them with the practicalities of living and by attending to the needs of all family members (Will, 1998). The main goal of family support services is to strengthen adults in their roles as parents, nurturers, and providers (Weissbourd & Kagan, 1989). Too often, family support services are not available within local communities.

Natural support systems are often diminished for families of children with serious emotional, behavioral, or physical disorders or handicaps because of the stigma of, or embarrassment about, their child's problems, or because caregivers have insufficient energy to reach out to others. Not surprisingly, most parents report that limited social support decreases their quality of life (Crowley & Kazdin, 1998) and that they feel less competent, more depressed, worried, and tired and have more problems with spouses and other family relationships than other parents (Farmer et al., 1997), although a few families do feel enriched by caring for these children (Yatchmenoff et al., 1998).

In a national survey of parents of children with an emotional or behavioral disorder, 72 percent of respondents indicated that emotional support (irrespective of its form) was the most helpful aspect of family support services (Friesen, 1990). Benefits included increased access to information, improved problem-solving skills, and more positive views about parenting and their children's behavior (Friesen & Koroloff, 1990).

Family support services occur in several forms: assistance with daily tasks and psychosocial support and counseling; informal or professional provision of services; and practical support such as housing assistance, food stamps, income support, or respite care (i.e., temporary relief for family members caring for individuals with disabilities).

Efforts to stop blaming parents for children's problems have resulted in parents becoming viewed less as patients than as partners, actively involved in every phase of the treatment process (e.g., home-based care, case management) and as a resource for their children, as discussed above. For the self-help and professionally led family support services described subsequently, parents may function either as partners or as providers. As "partners," parents act as a resource, active contributor, or decisionmaker; as "providers," they are viewed as contributing to the welfare and growth of other members of the family.

Results of research on the effectiveness of family services are only beginning to appear, in the form of some controlled studies and evaluations of support services for families of children with emotional and behavioral disorders (although there is a larger literature on families whose children have other types of disability and illness). Although this database on family support programs is still limited, many positive effects have been reported. The following paragraphs cover family support groups as well as concrete services. For the latter, only two types of interventions, respite care and the family associate, are included. Family therapy is covered in this chapter under Outpatient Treatment. Furthermore, several forms of parent training were found to be effective for individual diagnoses, such as conduct disorder (see section on Selected Mental Disorders in Children).

Family Support Groups

The primary focus of family support groups is to provide information and emotional support to members who share a common problem or concern (e.g., disability, substance abuse, bereavement). Support groups for families of children with emotional or behavioral disorders are expanding. Although there is a wide variation in membership, format, and duration of these groups, most share some characteristics. Usually, from 4 to 20 parents meet regularly to discuss the problems and issues associated with parenting a child with emotional and behavioral disorders and to provide mutual encouragement and suggestions for dealing with problematic situations. Support services may be informal, organized, and parent led and are often associated with organizations such as the National Mental Health Association, Children and Adults with Attention Deficit Disorders, the National Alliance for the Mentally Ill, or the Federation of Families for Children's Mental Health. Mental health professionals may also participate in support groups (Koroloff & Friesen, 1991).

It was found that support groups for parents of children hospitalized with mental illness make parents feel more positive about themselves and increase their understanding of and communication with their children (Dreier & Lewis, 1991). Participation in a six-session education and support group for parents of adolescents with schizophrenia led to increased relaxation and concentration, less worry, changed attitudes toward discipline, and greater ease in discussing feelings. The support from parents in similar situations was highly valued (Sheridan & Moore, 1991).

Another approach to support for parents of children receiving mental health services is education: knowledge of the services; skills needed to interact with the system; and the caregivers' confidence in their ability to collaborate with service providers (self-efficacy). A training curriculum for parents was tested in a randomized controlled trial involving more than

200 parents who either did or did not receive the training curriculum. Three-month and 1-year followup results demonstrated significant improvement in parents' knowledge and self-efficacy with the training curriculum, whereas there was no effect on the mental health status of their children, service use, or caregiver involvement in treatment (Heflinger & Bickman, 1996; Bickman et al., 1998).

Practical Support

Respite care is a type of concrete support that provides temporary relief to family caregivers. An investigation of the benefit of respite care is under way in New York in families with children at risk of hospital placement. When respite care was available, families preferred in-home to out-of-home care. The younger the children, the greater the child's functional impairment, and the fewer the social supports (Boothroyd et al., 1998), the more respite care was used. Outcomes have not yet been reported.

Another form of concrete support is exemplified by the Family Associate Intervention, which was developed in Oregon. It appears to be an inexpensive way to assist children in actually obtaining care after they have been identified as needing care. The goal is to use paraprofessionals (known as family associates), rather than professionals, to facilitate entry into an often intimidating service system. In a controlled study, family associates were found to be effective in helping families initiate mental health service use. Families receiving this support service were more likely to make and keep a first appointment at the mental health clinic. The effectiveness of the intervention was moderate but sufficient to encourage further development of such a low-cost intervention (Koroloff et al., 1996b; Elliot et al., 1998).

Integrated System Model

Within the public mental health system, the 1980s and 1990s have seen an increased emphasis on developing interagency community-based systems of care (Stroul & Friedman, 1986). This focus is driven by awareness that a large number of children are served in systems other than mental health, as well as by children's complex and interrelated needs, as indicated earlier (Friedman et al., 1996a, 1996b; Quinn & Epstein, 1998). In 1984, the Child and Adolescent Service System Program (CASSP) was launched to respond to the fragmentation of public services (Stroul & Friedman, 1986). It was funded by the services component of the National Institute of Mental Health, which later became the Center for Mental Health Services under the Alcohol and Drug Abuse and Mental Health Administration Reorganization Act of 1992 (Public Law 102-321).

CASSP recognized the need for public sector programs to become more integrated in their attempts to meet more fully and efficiently the needs of children and adolescents with a serious emotional disturbance and their families. This Federal program pioneered the concept of a "system of care" for this population, as delineated by Stroul and Friedman (1986, 1996). A system of care, described further below, is a comprehensive approach to coordinating and delivering a far-reaching array of services from multiple agencies. All 50 states and numerous communities have received CASSP grants to improve the organization of their response to the mental health needs of the most severely affected children and adolescents. Although CASSP principles have become a standard for program design, many communities do not offer comprehensive services according to the CASSP model.

CASSP provided the conceptual framework for the Robert Wood Johnson Foundation's Mental Health Services Program for Youth and the Annie E. Casey Foundation's Urban Mental Health Initiative. These foundation programs were devoted to the development of local interagency models (Cole, 1990). They were followed in 1992 by the authorization for what was to become the largest Federal program for child mental health, the Comprehensive Community Mental Health Services for Children and Their Families Program (also known as the Children's Services Program), sponsored by the Center for Mental Health Services (Public Law 102-321).

The Children's Services Program provides grants to states, communities, territories, and Indian tribes and tribal organizations to improve and expand systems of care to meet the needs of approximately 6.3 million children and adolescents with serious emotional disturbance and their families. The program now supports 45 sites across the country.

Built on the principles of CASSP, the Children's Services Program promotes the development of service delivery systems through a "system of care" approach. The system of care approach embraced by this initiative is defined as a comprehensive spectrum of mental health and other services and supports organized into a coordinated network to meet the diverse and changing needs of children and adolescents with serious emotional disturbance and their families (Stroul & Friedman, 1996). The system of care model is based on three main elements: (1) the mental health service system must be driven by the needs and the preferences of the child and family; (2) the locus and management of services must be within a multiagency collaborative environment, grounded in a strong community base; and (3) the services offered, the agencies participating, and the programs generated must be responsive to children's different cultural backgrounds. The Children's Services Program requires a national cross-site evaluation, which has been continuously implemented since the spring of 1994. Preliminary evidence from the uncontrolled evaluation indicates some improvements in outcomes, such as fewer law enforcement contacts and better school grades, living arrangements, and mental health status. As part of the evaluation, comparisons are being made between system of care sites and comparable communities without systems of care (Holden et al., 1999).

Effectiveness of Systems of Care

The previous sections have highlighted the transformations that have taken place since the early 1980s to create comprehensive, interagency, community-based systems of care. This section reviews the findings of research into the effectiveness of such systems of care as compared with more traditional systems.

Several studies on the effectiveness of systems of care have been conducted in recent years (Stroul, 1993a, 1993b; Bruns et al., 1995; Rosenblatt, 1998). Although findings are encouraging, their effectiveness has not yet been demonstrated conclusively, largely because evaluation studies have not had a control group. Most evaluations indicate that systems of care reduce rates of reinstitutionalization after discharge from residential settings, reduce out-of-state placements of children, and improve other individual outcomes such as number of behavior problems and satisfaction with services. After reviewing findings from the demonstration project of the Robert Wood Johnson Foundation, their own work in Vermont, research in California and Alaska, and early findings from the Fort Bragg evaluation, Bruns, Burchard, and Yoe (1995) conclude that "initial findings are encouraging, especially with the history of disappointing results of outcome studies for child and adolescent services" (p. 325). Details are available in the individual studies (Attkisson et al., 1997; Illback et al., 1998; Santarcangelo et al., 1998).

Reviews (Stroul, 1993a, 1993b; Rosenblatt, 1998) of uncontrolled studies of community-based systems of care showed that young people with serious emotional disturbances who were served under community-based systems of care consistently showed improvement across a range of outcomes. However, most of these studies used a so-called pre-post evaluation design that does not answer the question of whether the changes occurring over time (pre to post) are a consequence of the intervention or of the passage of time itself. Indeed, when comparison groups are studied, such as in the Fort Bragg demonstration project, results tend to be less favorable (see below).

The Fort Bragg Study

The Fort Bragg study, conducted by Bickman and his colleagues (Bickman et al., 1995; Bickman, 1996a; Hamner et al., 1997), merits detailed discussion because of the basic issues it raises and the controversy it engendered. The Fort Bragg study is an evaluation of a large-scale system change project initiated by the State of North Carolina and the Department of Defense in the early 1990s; it was designed to determine what systemic, clinical, and functional outcomes could be achieved if a wide range of individualized and family-centered services were provided without any barriers to their availability. The project involved replacing the traditional CHAMPUS benefit for children who were military dependents in the Fort Bragg area with a continuum of care that included a broad range of services, a single point of entry, comprehensive assessments, and no copayment or benefit limit. The provider agency at Fort Bragg was reimbursed for costs. The impact of this change on children was assessed by comparing outcomes at Fort Bragg with those at two other military installations in the Southeast where the traditional CHAMPUS benefit package remained in effect. The comparison sites restricted services to outpatient treatment, placement in a residential treatment center, or treatment in an inpatient hospital setting; regular copayment and benefit limits were in effect at the comparison sites.

Over a 3-year period, the evaluators collected service use, cost, satisfaction, clinical, and functional data for 984 young people served either at Fort Bragg (574) or the comparison sites (410). Overall, there were a number of favorable findings for the demonstration site at Fort Bragg: access for children was increased; children referred for services were indeed in need of help; parents and adolescents were more satisfied with the services they received than were parents and adolescents at the comparison sites; children received services sooner; care was provided in less restrictive environments; there was heavy use of intermediate-level services; fewer clients received only one session of outpatient treatment; overall, children stayed in treatment longer (although the length of stay in hospitals and residential treatment centers was shorter); and there were fewer disruptions in services (Bickman, 1996a). Thus, the major findings were that the expanded continuum of care resulted in greater access, higher satisfaction with services by patients, and less use of inpatient hospitalization and residential treatment. Bickman also concluded, however, that despite the fact that the intervention was well implemented at Fort Bragg, there were no differences between sites in clinical outcomes (emotional-behavioral functioning), and the cost was considerably greater at Fort Bragg.

The interpretation of the results by the project's principal investigator has generated much discussion and controversy in the children's mental health field, both in support of and questioning the study's conclusions (Friedman & Burns, 1996; Behar, 1997; Feldman, 1997; Hoagwood, 1997; Lourie, 1997; Pires, 1997; Saxe & Cross, 1997; Sechrest & Walsh, 1997; Weisz et al., 1997). Most of the controversy surrounds study interpretation, implementation, methodology, and the interpretation of the cost data (Behar, 1997; Feldman, 1997; Heflinger & Northrup, 1997; Langmeyer, 1997). Furthermore, it has been pointed out that Fort Bragg was not a multiagency community-based system of care (Friedman & Burns, 1996), a point that has been acknowledged by the principal investigator of the study (Bickman, 1996b). Overall, despite the controversy surrounding it, the Fort Bragg evaluation has challenged the notion that changes at the system level have consequences at the practice level and, ultimately, improve outcomes for children and families. The results have stimulated an increased focus on practice-level issues.

The Stark County Study

The shift in focus to the practice level is being reinforced by results from another study by Bickman and colleagues (1997, 1999) of children with emotional disturbances who were served in Stark County, Ohio. In this study, participating children were served within the public mental health system by a multiagency system of care; this was in contrast to the Fort Bragg sample of military dependents seen in a mental health-funded and -operated continuum of care. Children and families who consented to participate in the study were randomly assigned to one of two groups. The first group was immediately eligible to receive services within the existing community-based system of care in Stark County. Families in the second group were required to seek services on their own rather than to receive them within the system of care. The major differences in services provided were that significantly more children and families in the system of care group received case management and home visits than those in the comparison group. Findings indicate no differences in clinical or functional status 12 months after intake. These results are similar to those of the Fort Bragg study and suggest that attention should be paid to the effectiveness of services delivered *within* systems of care rather than only to the organization of these systems.

Summary: Effectiveness of Systems of Care

Collectively, the results of the evaluations of systems of care suggest that they are effective in achieving important system improvements, such as reducing use of residential placements, and out-of-state placements, and in achieving improvements in functional behavior. There also are indications that parents are more satisfied in systems of care than in more traditional service delivery systems. The effect of systems of care on cost is not yet clear, however. Nor has it yet been demonstrated that services delivered within a system of care will result in better clinical outcomes than services delivered within more traditional systems. There is clearly a need for more attention to be paid to the relationship between changes at the system level and changes at the practice level.

Conclusions

1. Childhood is characterized by periods of transition and reorganization, making it critical to assess the mental health of children and adolescents in the context of familial, social, and cultural expectations about age-appropriate thoughts, emotions, and behavior.
2. The range of what is considered "normal" is wide; still, children and adolescents can and do develop mental disorders that are more severe than the "ups and downs" in the usual course of development.
3. Approximately one in five children and adolescents experiences the signs and symptoms of a DSM-IV disorder during the course of a year, but only about 5 percent of all children experience what professionals term "extreme functional impairment."
4. Mental disorders and mental health problems appear in families of all social classes and of all backgrounds. No one is immune. Yet there are children who are at greatest risk by virtue of a broad array of factors. These include physical problems; intellectual disabilities (retardation); low birth weight; family history of mental and addictive disorders; multigenerational poverty; and caregiver separation or abuse and neglect.
5. Preventive interventions have been shown to be effective in reducing the impact of risk factors for mental disorders and improving social and emotional development by providing, for example, educational programs for young children, parent-education programs, and nurse home visits.
6. A range of efficacious psychosocial and pharmacologic treatments exists for many mental disorders in children, including attention-deficit/hyperactivity disorder, depression, and the disruptive disorders.
7. Research is under way to demonstrate the effectiveness of most treatments for children in actual practice settings (as opposed to evidence of "efficacy" in controlled research settings), and significant barriers exist to receipt of treatment.
8. Primary care and the schools are major settings for the potential recognition of mental disorders in children and adolescents, yet trained staff are limited, as are options for referral to specialty care.
9. The multiple problems associated with "serious emotional disturbance" in children and adolescents are best addressed with a "systems" approach in which multiple service sectors work in an organized, collaborative way. Research on the effectiveness of systems of care shows positive results for system outcomes and functional outcomes for children; however, the relationship between changes at the system level and clinical outcomes is still unclear.
10. Families have become essential partners in the delivery of mental health services for children and adolescents.
11. Cultural differences exacerbate the general problems of access to appropriate mental health

services. Culturally appropriate services have been designed but are not widely available.

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CHAPTER 4

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CHAPTER 4

ADULTS AND MENTAL HEALTH

Adulthood is a time for achieving productive vocations and for sustaining close relationships at home and in the community. These aspirations are readily attainable for adults who are mentally healthy. And they are within reach for adults who have mental disorders,-thanks to major strides in diagnosis, treatment, and service delivery.

This chapter reviews the current state of knowledge about mental health in adults, along with selected mental disorders: anxiety disorders, mood disorders, and schizophrenia. These disorders are highlighted largely because of their prevalence in the population and the burden of illness associated with each. The chapter then turns to service delivery, describing the effective organization and range of services for adults with the most severe mental disorders. It also reviews an array of other services and supports designed to provide comprehensive care beyond the formal therapeutic setting.

Chapter Overview

Mental health in adulthood is characterized by the successful performance of mental function, enabling individuals to cope with adversity and to flourish in their education, vocation, and personal relationships. These are the areas of functioning most widely recognized by the mental health field. Yet, from the perspective of different cultures, these measures may define the concept of mental health too narrowly. As noted in Chapter 2, many groups, particularly ethnic and racial minority group members, also emphasize community, spiritual, and religious ties as necessary for mental health. The mental health profession is becoming more aware of the importance of reaching out to other cultures; an innovation termed "linguistically and culturally competent services" is pertinent both to the field's conception of mental health and to the diagnosis and treatment of mental disorders.

An assortment of traits or personal characteristics have been viewed as contributing to mental health, including self-esteem, optimism, and resilience (Alloy & Abramson, 1988; Seligman, 1991; Institute of Medicine [IOM], 1994; Beardslee & Vaillant, 1997). These and related traits are seen as sources of personal resilience needed to weather the storms of stressful life events.

Stressful life events in adulthood include the breakup of intimate romantic relationships, death of a family member or friend, economic hardship, role conflict, work overload, racism and discrimination, poor physical health, accidental injuries, and intentional assaults on physical safety (Holmes & Rahe, 1967; Lazarus & Folkman, 1984; Kreiger et al., 1993). Stressful life events in adulthood also may reflect past events. Severe trauma in childhood, including sexual and physical abuse, may persist as a stressor into adulthood, or may make the individual more vulnerable to ongoing stresses (Browne & Finkelhor, 1986). Although some kinds of stressful life events are encountered almost universally, certain demographic groups have greater exposure and/or vulnerability to their cumulative impact. These groups include women, younger adults, unmarried adults, African Americans, and individuals of lower socioeconomic status (Ulbrich et al., 1989; McLeod & Kessler, 1990; Turner et al., 1995; Miranda & Green, 1999).

Anxiety disorders are the most prevalent mental disorders in adults (Regier et al., 1990). The anxiety disorders affect twice as many women as men. A broad category, anxiety disorders include panic disorder, phobias, obsessive-compulsive disorder, post-traumatic stress disorder, and generalized anxiety disorder.

among others. Underlying this heterogeneous group of disorders is a state of heightened arousal or fear in relation to stressful events or feelings. The biological manifestations of anxiety, which are grounded in the "fight-or-flight" response, are unmistakable: they include surge in heart rate, sweating, and tensing of muscles. But this is certainly not the whole picture. Although the full array of biological causes and correlates of anxiety are not yet in our grasp, numerous effective treatments for anxiety disorders exist now. Treatment draws on an assortment of psychosocial and pharmacological approaches, administered alone or in combination.

Mood disorders take a monumental toll in human suffering, lost productivity, and suicide. Moreover, when unrecognized, they can result in unnecessary health care use. Mood disorders rank among the top 10 causes of *worldwide* disability (Murray & Lopez, 1996). Major depression and bipolar disorder are the most familiar mood disorders, but there are others including cyclothymia (alternating manic and depressive states that, while protracted, do not meet criteria for bipolar disorder) and dysthymia (a chronic, albeit symptomatically milder form of depression). The causes of mood disorders are not fully known. They may be triggered by stressful life events and enduring stressful social conditions (e.g., poverty and discrimination). With the exception of bipolar disorder, they too, like the anxiety disorders, are twice as common in women as men. One subtype of mood disorder, seasonal affective disorder, in which episodes of depression tend to occur in the late fall and winter, is seven times more common in women than in men (Blumenthal, 1988). Many psychosocial and genetic factors interact to dictate the appearance and persistence of mood disorders, according to the biopsychosocial model presented in Chapter 2.

Mood disorders, like anxiety disorders, can be treated with a host of effective pharmacological and psychosocial treatments. Either type of treatment is effective for about 50 to 70 percent of patients in outpatient settings (Depression Guideline Panel, 1993). Severe depression seems to resolve more quickly with pharmacotherapy (Depression Guideline Panel, 1993) and may be helped further by multimodal therapy (the combination of pharmacotherapy and psychotherapy) (Thase et al., 1997b). Despite the efficacy of treatment, a surprising fraction of those with mood disorders go untreated (Katon et al., 1992; Narrow et al., 1993; Wells et al., 1994; Thase, 1996). The foremost barriers to treatment include cost, stigma, and problems in the organization of service systems that contribute to the underrecognition of these disorders.

Schizophrenia affects about 1 percent of the population, yet its severity and persistence reverberate throughout the mental health service system. Schizophrenia is marked by profound alterations in cognition and emotion. Symptoms frequently include hearing internal voices or experiencing other sensations not connected to an obvious source (hallucinations) and assigning unusual significance or meaning to normal events or holding false personal beliefs (delusions). The course of illness in schizophrenia is quite variable, with most people having periods of exacerbation and remission. Schizophrenia had once been thought to have a uniformly downhill course, but recent research dispels this view. Long-term followup studies show that many individuals with schizophrenia significantly improve and some recover (Ciompi, 1980; Harding et al., 1992). Although the causes of schizophrenia are not fully known, research points to the prominent role of genetic factors and to the impact of adverse environmental influences during early brain development (Tsuang et al., 1991; Weinberger & Lipska, 1995; Andreasen, 1997b). New pharmacological treatments are at least as effective as past pharmacological treatments with fewer troubling side effects.

Effective treatment of schizophrenia extends well beyond pharmacological therapy: it also includes psychosocial interventions, family interventions, and vocational and psychosocial rehabilitation. For those patients who are high service users, treatment should be coordinated by an interdisciplinary team that provides high-intensity, community-based services (Lehman & Steinwachs, 1998a). The prototype for this intensive case-management approach, which is useful for persons with other severe and persistent mental disorders as well, is assertive community treatment, described more thoroughly later in this chapter. Among the services included in this approach is substance abuse treatment. Its inclusion stems from findings that about *half* of patients with serious mental disorders (including schizophrenia) develop alcohol or other drug abuse problems (Drake & Osher, 1997). Even though research generated a range of recommendations for effective treatment of schizophrenia, it is alarming that less than 50 percent of patients actually receive many of the recommended treatments and that the gap was more pronounced in African Americans (Lehman & Steinwachs, 1998b).

The social consequences of serious mental disorders—family disruption, loss of employment and housing—can be calamitous. Comprehensive treatment, which includes services that exist outside the formal treatment system, is crucial to ameliorate symptoms, assist recovery, and, to the extent that these efforts are successful, redress stigma. Consumer self-help programs, family self-help, advocacy, and services for housing and vocational assistance complement and supplement the formal treatment system. Many of these services are operated by consumers, that is, people who use mental health services themselves. The logic behind their leadership in delivery of these services is that consumers are thought to be capable of engaging others with mental disorders, serving as role models, and increasing the sensitivity of service systems to the needs of people with mental disorders (Mowbray et al., 1996).

Mental Health in Adulthood

What constitutes mental health during the adult years? A widely used standard of mental health is the *absence* of a defined mental disorder. This standard has its limitations (discussed later), yet remains useful for epidemiological purposes. Epidemiology studies investigate the prevalence of mental disorders within several time frames: current, the past 12 months, and across a lifetime. Two well-designed national epidemiologic surveys estimate that about 80 percent of the adult population of the United States do not have a mental disorder during a year and hence may be considered "mentally healthy" (i.e., absence of a mental disorder) during any given year (Regier et al., 1993; Kessler et al., 1994). Thus, the popular notion that *everyone* is "dysfunctional" is far from the truth (Table 4-1). Yet, from time to time, many adults experience mental health problems.

Defining mental health by the absence of mental disorder does not convey the full picture of mental health. Among its limitations, this definition excludes adults with mental disorders who function well between episodes of illness. These people often are considered by themselves, and by coworkers, friends, and families, to be "mentally healthy" in spite of a history of mental illness and the risk of recurrence.

In addition to the mental health criteria cited earlier—that is, the successful performance of mental function, enabling individuals to cope with adversity and to flourish in their education, vocation, and personal relationships—a complementary approach defines the positive features of mental health in terms of attaining developmental milestones of adulthood, or in terms of displaying selected personality characteristics, traits, or attributes. Developmental theorist Erik Erikson viewed mental health in adulthood as achieving developmental tasks or milestones. According to Erikson's formulation and his subsequent empirical research on adult men, adulthood was the time for overcoming what he termed "psychosocial crises," the resolution of which led to satisfactory interpersonal and sexual relationships and to the pursuit of broader concerns for society and future generations (Erikson, 1963; Vaillant, 1977). However, these milestones, and the developmental theories that underpin them, have been criticized as reflecting the norms of European males rather than of women and other cultures.

Personality Traits

Mental health and mental illness can be seen as the product of various personality traits, behavior patterns, and other characteristics which have roots in the individual's prior life experiences or biology.

Table 4-1. Best estimate 1-year prevalence based on ECA and NCS, ages 18–54

	ECA Prevalence (%)	NCS Prevalence (%)	Best Estimate ** (%)
Any Anxiety Disorder	13.1	18.7	16.4
Simple Phobia	8.3	8.6	8.3
Social Phobia	2.0	7.4	2.0
Agoraphobia	4.9	3.7	4.9
GAD	(1.5)*	3.4	3.4
Panic Disorder	1.6	2.2	1.6
OCD	2.4	(0.9)*	2.4
PTSD	(1.9)*	3.6	3.6
Any Mood Disorder	7.1	11.1	7.1
MD Episode	6.5	10.1	6.5
Unipolar MD	5.3	8.9	5.3
Dysthymia	1.6	2.5	1.6
Biopolar I	1.1	1.3	1.1
Biopolar II	0.6	0.2	0.6
Schizophrenia	1.3	—	1.3
Nonaffective Psychosis	—	0.2	0.2
Somatization	0.2	—	0.2
ASP	2.1	—	2.1
Anorexia Nervosa	0.1	—	0.1
Severe Cognitive Impairment	1.2	—	1.2
Any Disorder	19.5	23.4	21.0

*Numbers in parentheses indicate the prevalence of the disorder without any comorbidity. These rates were calculated using the NCS data for GAD and PTSD, and the ECA data for OCD. The rates were not used in calculating the any anxiety disorder and any disorder totals for the ECA and NCS columns. The unduplicated GAD and PTSD rates were added to the best estimate total for any anxiety disorder (3.3%) and any disorder (1.5%).

**In developing best-estimate 1-year prevalence rates from the two studies, a conservative procedure was followed that had previously been used in an independent scientific analysis comparing these two data sets (Andrews, 1995). For any mood disorder and any anxiety disorder, the lower estimate of the two surveys was selected, which for these data was the ECA. The best estimate rates for the individual mood and anxiety disorders were then chosen from the ECA only, in order to maintain the relationships between the individual disorders. For other disorders that were not covered in both surveys, the available estimate was used.

Key to abbreviations: ECA, Epidemiologic Catchment Area; NCS, National Comorbidity Study; GAD, generalized anxiety disorder; OCD, obsessive-compulsive disorder; PTSD, post-traumatic stress disorder; MD, major depression; ASP, antisocial personality disorder.

Source: D. Regier, W. Narrow, & D. Rae, personal communication, 1999

Personality traits are thought to confer either beneficial or detrimental effects on mental health during adulthood. Here too, however, there may be insufficient attention to gender and culture. The culture-bound nature of much of behavior has limited widespread predictive validity of personality research (Mischel & Shoda, 1968). With this caveat in mind, a brief summary of healthy and maladaptive characteristics follows.

Self-Esteem

Self-esteem refers to an abiding set of beliefs about one's own worth, competence, and abilities to relate to others (Vaughan & Oldham, 1997). Self-esteem also has been conceptualized as buffering the individual from adverse life events. Emotional well-being is often associated with a slightly positive, yet realistic, outlook (Alloy & Abramson, 1988). The opposite outlook is

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characterized by pessimism, demoralization, or minor symptoms of anxiety and depression. One seminal aspect of self-esteem has garnered much research attention: self-efficacy (Bandura, 1977). Self-efficacy is defined as confidence in one's own abilities to cope with adversity, either independently or by obtaining appropriate assistance from others. Self-efficacy is a major component of the construct known as resilience (i.e., the ability to withstand and overcome adversity). Other components of resilience include intelligence and problem solving, although resilience is also facilitated by having adequate social support (Beardslee & Vaillant, 1997).

Neuroticism

Neuroticism is a construct that refers to a broad pattern of psychological, emotional, and psychophysiologic reactivity (Eysenck & Eysenck, 1975). The opposite of neuroticism is stability or equanimity, which are major components of mental health. A high level of neuroticism is associated with a predisposition toward recognizing the dangerous, harmful, or defeating aspects of a situation and the tendency to respond with worry, anticipatory anxiety, emotionality, pessimism, and dissatisfaction. Neuroticism is associated with a greater risk of early-onset depressive and anxiety disorders (Clark et al., 1994). Neuroticism also may be linked to a particular cognitive attributional style in which life events are perceived to be large in impact and more difficult to change (Alloy et al., 1984). For example, this attributional style is embodied by pessimists who see every setback or failure as lasting forever, undermining everything, and being their fault (Seligman, 1991). Neuroticism also is associated with more rigid or distorted attitudes and beliefs about one's competence (Beck, 1976).

Avoidance

Avoidance describes an exaggerated predisposition to withdraw from novel situations and to avoid personal challenges as threats. This is the behavioral state that often accompanies the distress of someone who has a high level of neuroticism and low self-efficacy (Vaughan & Oldham, 1997). Closely related to the characteristics of behavioral inhibition or introversion, the trait of avoidance appears to be partly inherited and is associated with shyness, anxiety, and depressive disorders in both childhood and adult life, as well as the subsequent development of substance abuse disorders (Vaughan & Oldham, 1997; Kagan et al., 1988). The people with low levels of harm avoidance are described as "healthy extroverts" and are characterized by confident, carefree, or outgoing behaviors.

Impulsivity

Impulsivity is a trait that is associated with poor modulation of emotions, especially anger, difficulty delaying gratification, and novelty seeking. There is some developmental continuity between high levels of impulsivity in childhood and several adult mental disorders, including attention deficit hyperactivity disorder, bipolar disorder, and substance abuse disorders (Svrakic et al., 1993; Rothbart & Ahadi, 1994). Impulsivity also is associated with physical abuse (both as victim and, subsequently, as perpetrator) and antisocial personality traits (Vaughan & Oldham, 1997).

Sociopathy

This set of traits and behaviors refers to the predisposition to engage in dishonest, hurtful, unfaithful, and at times dangerous conduct to benefit one's own ends. The opposite of sociopathy may be referred to as character or scrupulosity. In its full form, sociopathy is referred to as antisocial personality disorder (DSM-IV). Sociopathy is characterized by a tendency and ability to disregard laws and rules, difficulties reciprocating within empathic and intimate relationships, less internalization of moral standards (i.e., a weaker conscience or superego), and an insensitivity to the needs and rights of others. People scoring high in sociopathy often have problems with aggressivity and are overrepresented among criminal populations. Although not invariably associated with criminality, sociopathy is associated with problematic, unethical, and morally questionable conduct in the workplace and within social systems. Marked sociopathy is much more common among men than women, although several other disorders (borderline and histrionic personality disorders and somatization disorder) are overrepresented among women within the same families (Widiger & Costa, 1994).

In summary, the various traits and behavioral patterns that epitomize strong mental health do not, of course, exist in a vacuum: they develop in a social context, and they underpin people's ability to handle psychological and social adversity and the exposure to stressful life events. Furthermore, as reviewed in Chapter 3, severe or repeated trauma during youth may have enduring effects on both neurobiological and psychological development, altering stress responsivity and adult behavior patterns. Perhaps the best documented evidence of such enduring effects has been shown in young adults who experienced severe sexual or physical abuse in childhood. These individuals experience a greatly increased risk of mood, anxiety, and personality disorders throughout adult life.

Stressful Life Events

The most common psychological and social stressors in adult life include the breakup of intimate romantic relationships, death of a family member or friend, economic hardships, racism and discrimination, poor physical health, and accidental and intentional assaults on physical safety (Holmes & Rahe, 1967; Lazarus & Folkman, 1984; Kreiger et al., 1993). Although some stressors are so powerful that they would evoke significant emotional distress in most otherwise mentally healthy people, the majority of stressful life events do not invariably trigger mental disorders. Rather, they are more likely to spawn mental disorders in people who are vulnerable biologically, socially, and/or psychologically (Lazarus & Folkman, 1984; Brown & Harris, 1989; Kendler et al., 1995). Understanding variability among individuals to a stressful life event is a major challenge to research. Groups at greater statistical risk include women, young and unmarried people, African Americans, and individuals with lower socioeconomic status (Ulbrich et al., 1989; McLeod & Kessler, 1990; Turner et al., 1995; Miranda & Green, 1999).

Divorce is a common example. Approximately one-half of all marriages now end in divorce, and about 30 to 40 percent of those undergoing divorce report a significant increase in symptoms of depression and anxiety (Brown & Harris, 1989). Vulnerability to depression and anxiety is greater among those with a personal history of mental disorders earlier in life and is lessened by strong social support. For many, divorce conveys additional economic adversities and the stress of single parenting. Single mothers face twice the risk of depression as do married mothers (Brown & Moran, 1997).

The death of a child or spouse during early or midadult life is much less common than divorce but generally is of greater potency in provoking emotional distress (Kim & Jacobs, 1995). Rates of diagnosable mental disorders during periods of grief are attenuated by the convention not to diagnose depression during the first 2 months of bereavement (Clayton & Darvish, 1979). In fact, people are generally unlikely to seek professional treatment during bereavement unless the severity of the emotional and behavioral disturbance is incapacitating.

A majority of Americans never will confront the stress of surviving a severe, life-threatening accident or physical assault (e.g., mugging, robbery, rape); however, some segments of the population, particularly urban youths and young adults, have exposure rates as high as 25 to 30 percent (Helzer et al., 1987; Breslau et al., 1991). Life-threatening trauma frequently provokes emotional and behavioral reactions that jeopardize mental health. In the most fully developed form, this syndrome is called post-traumatic stress disorder (DSM-IV), which is described later in this chapter. Women are twice as likely as men to develop post-traumatic stress disorder following exposure to life-threatening trauma (Breslau et al., 1998.)

More familiar to many Americans is the chronic strain that poor physical health and relationship problems place on day-to-day well-being. Relationship problems include unsatisfactory intimate relationships; conflicted relationships with parents, siblings, and children; and "falling-out" with coworkers, friends, and neighbors. In mid-adult life, the stress of caretaking for elderly parents also becomes more common.

Relationship problems at least double the risk of developing a mental disorder, although they are less immediately threatening or potentially cataclysmic than divorce or the death of a spouse or child (Brown & Harris, 1989). Finally, cumulative adversity appears to be more potent than stressful events in isolation as a predictor of psychological distress and mental disorders (Turner & Lloyd, 1995).

Past Trauma and Child Sexual Abuse

Severe trauma in childhood may have enduring effects into adulthood (Browne & Finkelhor, 1986). Past trauma includes sexual and physical abuse, and parental death, divorce, psychopathology, and substance abuse (reviewed in Turner & Lloyd, 1995).

Child sexual abuse is one of the most common stressors, with effects that persist into adulthood. It disproportionately affects females. Although definitions are still evolving, child sexual abuse is often defined as forcible touching of breasts or genitals or forcible intercourse (including anal, oral, or vaginal sex) before the age of 16 or 18 (Goodman et al., 1997). Epidemiology studies of adults in varying segments of the community have found that 15 to 33 percent of females and 13 to 16 percent of males were sexually abused in childhood (Polusny & Follette, 1995). A recent, large epidemiological study of adults in the general community found a lower prevalence (12.8 percent for females and 4.3 percent for males); however, the definition of sexual abuse was more restricted than in past studies (MacMillan et al., 1997). Sexual abuse in childhood has a mean age of onset estimated at 7 to 9 years of age (Polusny & Follette, 1995). In over 25 percent of cases of child sexual abuse, the offense was committed by a parent or parent substitute (Sedlak & Broadhurst, 1996).

The long-term consequences of past childhood sexual abuse are profound, yet vary in expression. They range from depression and anxiety to problems with social functioning and adult interpersonal relationships (Polusny & Follette, 1995). Post-traumatic stress disorder is a common sequela, found in 33 to 86 percent of adult survivors of child sexual abuse (Polusny & Follette, 1995). In a recent review, Weiss et al. (1999) found that sexual abuse was a specific risk factor for adult-onset depression and twice as many women as men reported a history of abuse. Other long-term effects include self-destructive behavior, social isolation, poor sexual adjustment, substance abuse, and increased risk of revictimization (Browne & Finkelhor, 1986; Briere, 1992).

Very few treatments specifically for adult survivors of childhood abuse have been studied in randomized controlled trials (IOM, 1998). Group therapy and Interpersonal Transaction group therapy were found to be more effective for female survivors than an experimental control condition that offered a less appropriate intervention (Alexander et al., 1989, 1991). In the practice setting, most psychosocial and pharmacological treatments are tailored to the primary diagnosis, which, as noted above, varies widely and may not attend to the special needs of those also reporting abuse history.

Domestic Violence

Domestic violence is a serious and startlingly common public health problem with mental health consequences for victims, who are overwhelmingly female, and for children who witness the violence. Domestic violence (also known as intimate partner violence) features a pattern of physical and sexual abuse, psychological abuse with verbal intimidation, and/or social isolation or deprivation. Estimates are that 8 to 17 percent of women are victimized annually in the United States (Wilt & Olsen, 1996). Pinpointing the prevalence is hindered by variations in the way domestic violence is defined and by problems in detection and underreporting. Women are often fearful that their reporting of domestic violence will precipitate retaliation by the batterer, a fear that is not unwarranted (Sisley et al., 1999).

Victims of domestic violence are at increased risk for mental health problems and disorders as well as physical injury and death. Domestic violence is considered one of the foremost causes of serious injury to women ages 15 to 44, accounting for about 30 percent of all acute injuries to women seen in emergency departments (Wilt & Olsen, 1996). According to the U.S. Department of Justice, females were victims in about 75 percent of the almost 2,000 homicides between intimates in 1996 (cited in Sisley et al., 1999). The mental health consequences of domestic violence include depression, anxiety disorders (e.g., post-traumatic stress disorder), suicide, eating disorders, and substance abuse (IOM, 1998; Eisenstat & Bancroft, 1999). Children who witness domestic violence may suffer acute and long-term emotional disturbances, including nightmares, depression, learning difficulties, and aggressive behavior. Children also become at risk for subsequent use of violence against their dating partners and wives (el-Bayoumi et al., 1998; NRC, 1998; Sisley et al., 1999).

Mental health interventions for victims, children, and batterers are highly important. Individual counseling and peer support groups are the interventions most frequently used by battered women. However, there is a lack of carefully controlled, methodologically robust studies of interventions and their outcomes, according to a report by the Institute of Medicine and National Research Council (IOM, 1998). A research agenda for violence against women was developed (IOM, 1996) and has served as an impetus for an ongoing research program sponsored by the U.S. Departments of Justice and Health and Human Services. Clearly, there is an urgent need for development and rigorous evaluation of prevention programs to safeguard against intimate partner violence and its impact on children.

Interventions for Stressful Life Events

Stressful life events, even for those at the peak of mental health, erode quality of life and place people at risk for symptoms and signs of mental disorders. There is an ever-expanding list of formal and informal interventions to aid individuals coping with adversity. Sources of informal interventions include family and friends, education, community services, self-help groups, social support networks, religious and spiritual endeavors, complementary healers, and physical activities. As valuable as these activities may be for promoting mental health, they have received less research attention than have interventions for mental disorders. Nevertheless, there are selected interventions to help people cope with stressors, such as bereavement programs and programs for caregivers (see Chapter 5) as well as couples therapy and physical activity.

Couples therapy is the umbrella term applied to interventions that aid couples in distress. The best studied interventions are behavioral couples therapy, cognitive-behavioral couples therapy, and emotion-focused couples therapy. A recent review article evaluated the body of evidence on the effectiveness of couples therapy and programs to prevent marital discord (Christensen & Heavey, 1999). The review found that about 65 percent of couples in therapy did improve, whereas 35 percent of control couples also improved. Couples therapy ameliorates relationship distress and appears to alleviate depression. The gains from couples therapy generally last through 6 months, but there are few long-term assessments (Christensen & Heavey, 1999). Similarly, interventions to prevent marital discord yield short-term improvements in marital adjustment and stability, but there is insufficient study of long-term outcomes. The prevention programs receiving the most study are the Couple Communication Program, Relationship Enhancement, and the Prevention and Relationship Enhancement Program (Christensen & Heavey, 1999). Greater research is needed to overcome gaps in knowledge and to extend findings to a broader array of programs, to diverse populations of couples, and to a wider set of outcomes, including effects on children.

Physical activities are a means to enhance somatic health as well as to deal with stress. A recent Surgeon General's Report on Physical Activity and Health evaluated the evidence for physical activities serving to enhance mental health (U.S. Department of Health and Human Services [DHHS], 1996). Aerobic physical activities, such as brisk walking and running, were found to improve mental health for people who report *symptoms* of anxiety and depression and for those who are diagnosed with some forms of depression. The mental health benefits of physical activity for individuals in relatively good physical and mental health were not as evident, but the studies did not have sufficient rigor from which to draw unequivocal conclusions (DHHS, 1996).

Prevention of Mental Disorders

A promising development in prevention of a specific mental disorder in adults occurred with the publication of results from the San Francisco Depression Research Project (Munoz et al., 1995). This study investigated 150 primary care patients who did not meet diagnostic criteria for depression and who were being seen in a public clinic for other problems. They were randomized to either psychoeducation—an 8-week cognitive behavioral course to help them control and manage moods—or to a control condition. One year later, those who received psychoeducation were found to have developed significantly fewer depression symptoms than members of the control group. This trial is noteworthy in two major respects: it was a randomized controlled trial and its participants were low-income individuals, with high representation of all major minority groups. Low-income individuals are considered a high-risk population because of studies documenting their higher prevalence of mental disorders. This study demonstrated in a methodologically rigorous fashion that depression may be preventable in some cases. It serves as a model for extending the concept of prevention to many mental disorders. Prevention research is vitally important and needs to be enhanced.

Anxiety Disorders

The anxiety disorders are the most common, or frequently occurring, mental disorders. They encompass a group of conditions that share extreme or pathological anxiety as the principal disturbance of mood or emotional tone. Anxiety, which may be understood as the pathological counterpart of normal fear, is manifest by disturbances of mood, as well as of thinking, behavior, and physiological activity.

Types of Anxiety Disorders

The anxiety disorders include panic disorder (with and without a history of agoraphobia), agoraphobia (with and without a history of panic disorder), generalized anxiety disorder, specific phobia, social phobia, obsessive-compulsive disorder, acute stress disorder, and post-traumatic stress disorder (DSM-IV). In addition, there are adjustment disorders with anxious features, anxiety disorders due to general medical conditions, substance-induced anxiety disorders, and the residual category of anxiety disorder not otherwise specified (DSM-IV).

Anxiety disorders not only are common in the United States, but they are ubiquitous across human cultures (Regier et al., 1993; Kessler et al., 1994; Weissman et al., 1997). In the United States, 1-year prevalence for all anxiety disorders among adults ages 18 to 54 exceeds 16 percent (Table 4-1), and there is significant overlap or comorbidity with mood and substance abuse disorders (Regier et al., 1990; Goldberg & Lecrubier, 1995; Magee et al., 1996). The longitudinal course of these disorders is characterized by relatively early ages of onset, chronicity, relapsing or recurrent episodes of illness, and periods of disability (Keller & Hanks, 1994; Gorman & Coplan, 1996; Liebowitz, 1997; Marcus et al., 1997). Although few psychological autopsy studies of adult suicides have included a focus on comorbid conditions (Conwell & Brent, 1995), it is likely that the rate of comorbid anxiety in suicide is underestimated. Panic disorder and agoraphobia, particularly, are associated with increased risks of attempted suicide (Hornig & McNally, 1995; American Psychiatric Association, 1998).

Panic Attacks and Panic Disorder

A panic attack is a discrete period of intense fear or discomfort that is associated with numerous somatic and cognitive symptoms (DSM-IV). These symptoms include palpitations, sweating, trembling, shortness of breath, sensations of choking or smothering, chest pain, nausea or gastrointestinal distress, dizziness or lightheadedness, tingling sensations, and chills or blushing and "hot flashes." The attack typically has an abrupt onset, building to maximum intensity within 10 to 15 minutes. Most people report a fear of dying, "going crazy," or losing control of emotions or behavior. The experiences generally provoke a strong urge to escape or flee the place where the attack begins and, when associated with chest pain or shortness of breath, frequently results in seeking aid from a hospital emergency room or other type of urgent assistance. Yet an attack rarely lasts longer than 30 minutes. Current diagnostic practice specifies that a panic attack must be characterized by at least four of the associated somatic and cognitive symptoms described above. The panic attack is distinguished from other forms of anxiety by its intensity and its sudden, episodic nature. Panic attacks may be further characterized by the relationship between the onset of the attack and the presence or absence of situational factors. For example, a panic attack may be described as *unexpected, situationally bound*, or *situationally predisposed* (usually, but not invariably occurring in a particular situation). There are also attenuated or "limited symptom" forms of panic attacks.

Panic attacks are not always indicative of a mental disorder, and up to 10 percent of otherwise healthy people experience an isolated panic attack per year (Barlow, 1988; Klerman et al., 1991). Panic attacks also are not limited to panic disorder. They commonly occur in the course of social phobia, generalized anxiety disorder, and major depressive disorder (DSM-IV).

Panic disorder is diagnosed when a person has experienced at least two unexpected panic attacks *and* develops persistent concern or worry about having further attacks or changes his or her behavior to avoid or minimize such attacks. Whereas the number and severity of the attacks varies widely, the concern and avoidance behavior are essential features. The diagnosis is inapplicable when the attacks are presumed to be caused by a drug or medication or a general medical disorder, such as hyperthyroidism.

Lifetime rates of panic disorder of 2 to 4 percent and 1-year rates of about 2 percent are documented consistently in epidemiological studies (Kessler et al., 1994; Weissman et al., 1997) (Table 4-1). Panic disorder is frequently complicated by major depressive disorder (50 to 65 percent lifetime comorbidity rates) and alcoholism and substance abuse disorders (20 to 30 percent comorbidity) (Keller & Hanks, 1994; Magee et al., 1996; Liebowitz, 1997). Panic disorder is also concomitantly diagnosed, or co-occurs, with other specific anxiety disorders, including social phobia (up to 30 percent), generalized anxiety disorder (up to 25 percent), specific phobia (up to 20 percent), and obsessive-compulsive disorder (up to 10 percent) (DSM-IV). As discussed subsequently, approximately one-half of people with panic disorder at some point develop such severe avoidance as to warrant a separate description, panic disorder with agoraphobia.

Panic disorder is about twice as common among women as men (American Psychiatric Association, 1998). Age of onset is most common between late adolescence and midadult life, with onset relatively uncommon past age 50. There is developmental continuity between the anxiety syndromes of youth, such as separation anxiety disorder. Typically, an early age of onset of panic disorder carries greater risks of comorbidity, chronicity, and impairment. Panic disorder is a familial condition and can be distinguished from depressive disorders by family studies (Rush et al., 1998).

Agoraphobia

The ancient term agoraphobia is translated from Greek as fear of an open marketplace. Agoraphobia today describes severe and pervasive anxiety about being in situations from which escape might be difficult or avoidance of situations such as being alone outside of the home, traveling in a car, bus, or airplane, or being in a crowded area (DSM-IV).

Most people who present to mental health specialists develop agoraphobia after the onset of panic disorder (American Psychiatric Association, 1998). Agoraphobia is best understood as an adverse behavioral outcome of repeated panic attacks and the subsequent worry, preoccupation, and avoidance (Barlow, 1988). Thus, the formal diagnosis of panic disorder with agoraphobia was established. However, for those people in communities or clinical settings who do not meet full criteria for panic disorder, the formal diagnosis of agoraphobia without history of panic disorder is used (DSM-IV).

The 1-year prevalence of agoraphobia is about 5 percent (Table 4-1). Agoraphobia occurs about two times more commonly among women than men (Magee et al., 1996). The gender difference may be attributable to social-cultural factors that encourage, or permit, the greater expression of avoidant coping strategies by women (DSM-IV), although other explanations are possible.

Specific Phobias

These common conditions are characterized by marked fear of specific objects or situations (DSM-IV). Exposure to the object of the phobia, either in real life or via imagination or video, invariably elicits intense anxiety, which may include a (situationally bound) panic attack. Adults generally recognize that this intense fear is irrational. Nevertheless, they typically avoid the phobic stimulus or endure exposure with great difficulty. The most common specific phobias include the following feared stimuli or situations: animals (especially snakes, rodents, birds, and dogs); insects (especially spiders and bees or hornets); heights; elevators; flying; automobile driving; water; storms; and blood or injections.

Approximately 8 percent of the adult population suffers from one or more specific phobias in 1 year (Table 4-1). Much higher rates would be recorded if less rigorous diagnostic requirements for avoidance or functional impairment were employed. Typically, the specific phobias begin in childhood, although there is a second "peak" of onset in the middle 20s of adulthood (DSM-IV). Most phobias persist for years or even decades, and relatively few remit spontaneously or without treatment.

The specific phobias generally do not result from exposure to a single traumatic event (i.e., being bitten by a dog or nearly drowning) (Marks, 1969). Rather, there is evidence of phobia in other family members and social or vicarious learning of phobias (Cook & Mineka, 1989). Spontaneous, unexpected panic attacks also appear to play a role in the development of specific phobia, although the particular pattern of avoidance is much more focal and circumscribed.

Social Phobia

Social phobia, also known as social anxiety disorder, describes people with marked and persistent anxiety in social situations, including performances and public speaking (Ballenger et al., 1998). The critical element of the fearfulness is the possibility of embarrassment or ridicule. Like specific phobias, the fear is recognized by adults as excessive or unreasonable, but the dreaded social situation is avoided or is tolerated with great discomfort. Many people with social phobia are preoccupied with concerns that others will see their anxiety symptoms (i.e., trembling, sweating, or blushing); or notice their halting or rapid speech; or judge them to be weak, stupid, or "crazy." Fears of fainting, losing control of bowel or bladder function, or having one's mind going blank are also not uncommon. Social phobias generally are associated with significant anticipatory anxiety for days or weeks before the dreaded event, which in turn may further handicap performance and heighten embarrassment.

The 1-year prevalence of social phobia ranges from 2 to 7 percent (Table 4-1), although the lower figure probably better captures the number of people who experience significant impairment and distress. Social phobia is more common in women (Wells et al., 1994). Social phobia typically begins in childhood or adolescence and, for many, it is associated with the traits of shyness and social inhibition (Kagan et al., 1988). A public humiliation, severe embarrassment, or other stressful experience may provoke an intensification of difficulties (Barlow, 1988). Once the disorder is established, complete remissions are uncommon without treatment. More commonly, the severity of symptoms and impairments tends to fluctuate in relation to vocational demands and the stability of social relationships. Preliminary data suggest social phobia to be familial (Rush et al., 1998).

Generalized Anxiety Disorder

Generalized anxiety disorder is defined by a protracted ($\geq$ 6 months' duration) period of anxiety and worry, accompanied by multiple associated symptoms (DSM-IV). These symptoms include muscle tension, easy fatiguability, poor concentration, insomnia, and irritability. In youth, the condition is known as overanxious disorder of childhood. In DSM-IV, an essential feature of generalized anxiety disorder is that the anxiety and worry cannot be attributable to the more focal distress of panic disorder, social phobia, obsessive-compulsive disorder, or other conditions. Rather, as implied by the name, the excessive worries often pertain to many areas, including work, relationships, finances, the well-being of one's family, potential misfortunes, and impending deadlines. Somatic anxiety symptoms are common, as are sporadic panic attacks.

Generalized anxiety disorder occurs more often in women, with a sex ratio of about 2 women to 1 man (Brawman-Mintzer & Lydiard, 1996). The 1-year population prevalence is about 3 percent (Table 4-1). Approximately 50 percent of cases begin in childhood or adolescence. The disorder typically runs a fluctuating course, with periods of increased symptoms usually associated with life stress or impending difficulties. There does not appear to be a specific familial association for general anxiety disorder. Rather, rates of other mood and anxiety disorders typically are greater among first-degree relatives of people with generalized anxiety disorder (Kendler et al., 1987).

Obsessive-Compulsive Disorder

Obsessions are recurrent, intrusive thoughts, impulses, or images that are perceived as inappropriate, grotesque, or forbidden (DSM-IV). The obsessions, which elicit anxiety and marked distress, are termed "ego-alien" or "ego-dystonic" because their content is quite unlike the thoughts that the person usually has. Obsessions are perceived as uncontrollable, and the sufferer often fears that he or she will lose control and act upon such thoughts or impulses. Common themes include contamination with germs or body fluids, doubts (i.e., the worry that something important has been overlooked or that the sufferer has unknowingly inflicted harm on someone), order or symmetry, or loss of control of violent or sexual impulses.

Compulsions are repetitive behaviors or mental acts that reduce the anxiety that accompanies an obsession or "prevent" some dreaded event from happening (DSM-IV). Compulsions include both overt behaviors, such as hand washing or checking, and mental acts including counting or praying. Not uncommonly, compulsive rituals take up long periods of time, even hours, to complete. For example, repeated hand washing, intended to remedy anxiety about contamination, is a common cause of contact dermatitis.

Although once thought to be rare, obsessive-compulsive disorder has now been documented to have a 1-year prevalence of 2.4 percent (Table 4-1). Obsessive-compulsive disorder is equally common among men and women.

Obsessive-compulsive disorder typically begins in adolescence to young adult life (males) or in young adult life (females) (Burke et al., 1990; DSM-IV). For most, the course is fluctuating and, like generalized anxiety disorder, symptom exacerbations are usually associated with life stress. Common comorbidities include major depressive disorder and other anxiety disorders. Approximately 20 to 30 percent of people in clinical samples with obsessive-compulsive disorder report a past history of tics, and about one-quarter of these people meet the full criteria for Tourette's disorder (DSM-IV). Conversely, up to 50 percent of people with Tourette's disorder develop obsessive-compulsive disorder (Pitman et al., 1987).

Obsessive-compulsive disorder has a clear familial pattern and somewhat greater familial specificity than most other anxiety disorders. Furthermore, there is an increased risk of obsessive-compulsive disorder among first-degree relatives with Tourette's disorder. Other mental disorders that may fall within the spectrum of obsessive-compulsive disorder include trichotillomania (compulsive hair pulling), compulsive shoplifting, gambling, and sexual behavior disorders (Hollander, 1996). The latter conditions are somewhat discrepant because the compulsive behaviors are less ritualistic and yield some outcomes that are pleasurable or gratifying. Body dysmorphic disorder is a more circumscribed condition in which the compulsive and obsessive behavior centers around a preoccupation with one's appearance (i.e., the syndrome of imagined ugliness) (Phillips, 1991).

Acute and Post-Traumatic Stress Disorders

Acute stress disorder refers to the anxiety and behavioral disturbances that develop within the first month after exposure to an extreme trauma. Generally, the symptoms of an acute stress disorder begin during or shortly following the trauma. Such extreme traumatic events include rape or other severe physical assault, near-death experiences in accidents, witnessing a murder, and combat. The symptom of dissociation, which reflects a perceived detachment of the mind from the emotional state or even the body, is a critical feature. Dissociation also is characterized by a sense of the world as a dreamlike or unreal place and may be accompanied by poor memory of the specific events, which in severe form is known as dissociative amnesia. Other features of an acute stress disorder include symptoms of generalized anxiety and hyperarousal, avoidance of situations or stimuli that elicit memories of the trauma, and persistent, intrusive recollections of the event via flashbacks, dreams, or recurrent thoughts or visual images.

If the symptoms and behavioral disturbances of the acute stress disorder persist for more than 1 month, and if these features are associated with functional impairment or significant distress to the sufferer, the diagnosis is changed to post-traumatic stress disorder. Post-traumatic stress disorder is further defined in DSM-IV as having three subforms: acute[1] (< 3 months' duration), chronic (≥ 3 months' duration), and delayed onset (symptoms began at least 6 months after exposure to the trauma).

By virtue of the more sustained nature of post-traumatic stress disorder (relative to acute stress disorder), a number of changes, including decreased self-esteem, loss of sustained beliefs about people or society, hopelessness, a sense of being permanently damaged, and difficulties in previously established relationships, are typically observed. Substance abuse often develops, especially involving alcohol, marijuana, and sedative-hypnotic drugs.

About 50 percent of cases of post-traumatic stress disorder remit within 6 months. For the remainder, the disorder typically persists for years and can dominate the sufferer's life. A longitudinal study of Vietnam veterans, for example, found 15 percent of veterans to be suffering from post-traumatic stress disorder 19 years after combat exposure (cited in McFarlane & Yehuda, 1996). In the general population, the 1-year prevalence is about 3.6 percent, with women having almost twice the prevalence of men (Kessler et al., 1995) (Table 4-1). The highest rates of post-traumatic stress disorder are found among women who are victims of crime, especially rape, as well as among torture and concentration camp survivors (Yehuda, 1999). Overall, among those exposed to extreme trauma, about 9 percent develop post-traumatic stress disorder (Breslau et al., 1998).

Etiology of Anxiety Disorders

The etiology of most anxiety disorders, although not fully understood, has come into sharper focus in the last decade. In broad terms, the likelihood of developing anxiety involves a combination of life experiences, psychological traits, and/or genetic factors. The anxiety disorders are so heterogeneous that the relative roles of these factors are likely to differ. Some anxiety disorders, like panic disorder, appear to have a stronger genetic basis than others (National Institute of Mental Health [NIMH], 1998), although actual genes have not been identified. Other anxiety disorders are more rooted in stressful life events.

It is not clear why females have higher rates than males of most anxiety disorders, although some theories have suggested a role for the gonadal steroids. Other research on women's responses to stress also suggests that women experience a wider range of life events (e.g., those happening to friends) as stressful as compared with men who react to a more limited range of stressful events, specifically those affecting themselves or close family members (Maciejewski et al., 1999).

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[1] The acute subform of post-traumatic stress disorder is distinct from acute stress disorder because the latter resolves by the end of the first month, whereas the former persists until 3 months. If the condition persists after 3 months duration, the diagnosis is again changed to the chronic post-traumatic stress disorder subform (DSM-IV).

What the myriad of anxiety disorders have in common is a state of increased arousal or fear (Barbee, 1998). Anxiety disorders often are conceptualized as an abnormal or exaggerated version of arousal. Much is known about arousal because of decades of study in animals[2] and humans of the so-called "fight-or-flight response," which also is referred to as the acute stress response. The acute stress response is critical to understanding the normal response to stressors and has galvanized research, but its limitations for understanding anxiety have come to the forefront in recent years, as this section later explains.

In common parlance, the term "stress" refers either to the external stressor, which can be physical or psychosocial in nature, as well as to the internal response to the stressor. Yet researchers distinguish the two, calling the stressor the stimulus and the body's reaction the stress response. This is an important distinction because in many anxiety states there is no immediate external stressor. The following paragraphs describe the biology of the acute stress response, as well as its limitations, in understanding human anxiety. Emerging views about the neurobiology of anxiety attempt to integrate and understand psychosocial views of anxiety and behavior in relation to the structure and function of the central and peripheral nervous system.

Acute Stress Response

When a fearful or threatening event is perceived, humans react innately to survive: they either are ready for battle or run away (hence the term "fight-or-flight response"). The nature of the acute stress response is all too familiar. Its hallmarks are an almost instantaneous surge in heart rate, blood pressure, sweating, breathing, and metabolism, and a tensing of muscles. Enhanced cardiac output and accelerated metabolism are essential for mobilizing fast action. The host of physiological changes activated by a stressful event are unleashed in part by activation of a nucleus in the brain stem called the locus ceruleus. This nucleus is the origin of most norepinephrine pathways in the brain. Neurons using norepinephrine as their neurotransmitter project bilaterally from the locus ceruleus along distinct pathways to the cerebral cortex, limbic system, and the spinal cord, among other projections.

Normally, when someone is in a serene, unstimulated state, the "firing" of neurons in the locus ceruleus is minimal. A novel stimulus, once perceived, is relayed from the sensory cortex of the brain through the thalamus to the brain stem. That route of signaling increases the rate of noradrenergic activity in the locus ceruleus, and the person becomes alert and attentive to the environment. If the stimulus is perceived as a threat, a more intense and prolonged discharge of the locus ceruleus activates the sympathetic division of the autonomic nervous system (Thase & Howland, 1995). The activation of the sympathetic nervous system leads to the release of norepinephrine from nerve endings acting on the heart, blood vessels, respiratory centers, and other sites. The ensuing physiological changes constitute a major part of the acute stress response. The other major player in the acute stress response is the hypothalamic-pituitary-adrenal axis, which is discussed in the next section.

In the 1980s, the prevailing view was that excess discharge of the locus ceruleus with the acute stress response was a major contributor to the etiology of anxiety (Coplan & Lydiard, 1998). Yet over the past decade, the limitations of the acute stress response as a model for understanding anxiety have become more apparent. The first and most obvious limitation is that the acute stress response relates to *arousal* rather than *anxiety*. Anxiety differs from arousal in several ways (Barlow, 1988; Nutt et al., 1998). First, with anxiety, the concern about the stressor is out of proportion to the realistic threat. Second, anxiety is often associated with elaborate mental and behavioral activities designed to avoid the unpleasant symptoms of a full-blown anxiety or panic attack. Third, anxiety is usually longer lived than arousal. Fourth, anxiety can occur without exposure to an external stressor.

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[2] Anxiety is one of the few mental disorders for which animal models have beendeveloped. Researchers can reproduce some of the symptoms of human anxiety in animals by introducing different types of stressors, either physical or psychosocial.

Other limitations of this model became evident from a lack of support from clinical and basic research (Coplan & Lydiard, 1998). Furthermore, with its emphasis on the neurotransmitter norepinephrine, the model could not explain why medications that acted on the neurotransmitter serotonin (the selective serotonin reuptake inhibitors, or SSRIs) helped to alleviate anxiety symptoms. In fact, these medications are becoming the first-line treatment for anxiety disorders (Kent et al., 1998). To probe the etiology of anxiety, researchers began to devote their energies to the study of other brain circuits and the neurotransmitters on which they rely. The locus ceruleus still participates in anxiety but is understood to play a lesser role.

New Views About the Anatomical and Biochemical Basis of Anxiety

An exciting new line of research proposes that anxiety engages a wide range of neurocircuits. This line of research catapults to prominence two key regulatory centers found in the cerebral hemispheres of the brain—the hippocampus and the amygdala. These centers, in turn, are thought to activate the hypothalamic-pituitary-adrenocortical (HPA) axis[3] (Goddard & Charney, 1997; Coplan & Lydiard, 1998; Sullivan et al., 1998). Researchers have long established the contribution of the HPA axis to anxiety but have been perplexed by how it is regulated. They are buoyed by new findings about the roles of the hippocampus and the amygdala.

The hippocampus and the amygdala govern memory storage and emotions, respectively, among their other functions. The hippocampus is considered important in verbal memory, especially of time and place for events with strong emotional overtones (McEwen, 1998). The hippocampus and amygdala are major nuclei of the limbic system, a pathway known to underlie emotions. There are anatomical projections between the hippocampus, amygdala, and hypothalamus (Jacobson & Sapolsky, 1991; Charney & Deutch, 1996; Coplan & Lydiard, 1998).

Studies of emotional processing in rodents (LeDoux, 1996; Rogan & LeDoux, 1996; Davis, 1997) and in humans with brain lesions (Adolphs et al., 1998) have identified the amygdala as critical to fear responses. Sensory information enters the lateral amygdala, from which processed information is passed to the central nucleus, the major output nucleus of the amygdala. The central nucleus projects, in turn, to multiple brain systems involved in the physiologic and behavioral responses to fear. Projections to different regions of the hypothalamus activate the sympathetic nervous system and induce the release of stress hormones, such as CRH.[4] The production of CRH in the paraventricular nucleus of the hypothalamus activates a cascade leading to release of glucocorticoids from the adrenal cortex. Projections from the central nucleus innervate different parts of the periaqueductal gray matter, which initiates descending analgesic responses (involving the body's endogenous opioids) that can suppress pain in an emergency, and which also activates species-typical defensive responses (e.g., many animals freeze when fearful).

Anxiety differs from fear in that the fear-producing stimulus is either not present or not immediately threatening, but in anticipation of danger, the same arousal, vigilance, physiologic preparedness, and negative affects and cognitions occur. Different types of internal or external factors or triggers act to produce the anxiety symptoms of panic disorder, agoraphobia, post-traumatic stress disorder, specific phobias, and generalized anxiety disorder, and the prominent anxiety that commonly occurs in major depression. It is currently a matter of research to determine whether dysregulation of these fear pathways leads to the symptoms of anxiety disorders. It has now been established, using noninvasive neuroimaging, that the human amygdala is also involved in fear responses. Fearful facial expressions have been shown to activate the amygdala in MRI studies of normal human subjects (Breiter et al., 1996). Functional imaging studies in anxiety disorders, such as PET studies of brain activation in phobias (Rauch et al., 1995), are also beginning to investigate the precise neural circuits involved in the anxiety disorders.

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[3] Hypothalamus and the pituitary gland, and then the cortex, or outer layer, of the adrenal gland. Upon stimulation by the pituitary hormone ACTH, the adrenal cortex releases glucocorticoids into the circulation.

[4] Also known as corticotropin-releasing factor

What is especially exciting is that neuroimaging has furnished direct evidence in humans of the damaging effects of glucocorticoids. In people with post-traumatic stress disorder, neuroimaging studies have found a reduction in the size of the hippocampus. The reduced volume appears to reflect the atrophy of dendrites—the receptive portion of nerve cells—in a select region of the hippocampus. Similarly, animals exposed to chronic psychosocial stress display atrophy in the same hippocampal region (McEwen & Magarinos, 1997). Stress-induced increases in glucocorticoids are thought to be responsible for the atrophy (McEwen, 1998). If the hippocampus is impaired, the individual is thought to be less able to draw on memory to evaluate the nature of the stressor (McEwen, 1998).

Neurotransmitter Alterations

There are many neurotransmitter alterations in anxiety disorders. In keeping with the broader view of anxiety, at least five neurotransmitters are perturbed in anxiety: serotonin, norepinephrine, gamma-aminobutyric acid (GABA), corticotropin-releasing hormone (CRH),[5] and cholecystokinin (Coplan & Lydiard 1998; Rush et al., 1998). There is such careful orchestration between these neurotransmitters that changes in one neurotransmitter system invariably elicit changes in another, including extensive feedback mechanisms. Serotonin and GABA are inhibitory neurotransmitters that quiet the stress response (Rush et al., 1998). All of these neurotransmitters have become important targets for therapeutic agents either already marketed or in development (as discussed in the section on treatment of anxiety disorders).

Psychological Views of Anxiety

There are several major psychological theories of anxiety: psychoanalytic and psychodynamic theory, behavioral theories, and cognitive theories (Thorn et al., 1999). Psychodynamic theories have focused on symptoms as an expression of underlying conflicts (Rush et al., 1998; Thorn et al., 1999). Although there are no empirical studies to support these psychodynamic theories, they are amenable to scientific study (Kandel, 1999) and some therapists find them useful. For example, ritualistic compulsive behavior can be viewed as a result of a specific defense mechanism that serves to channel psychic energy away from conflicted or forbidden impulses. Phobic behaviors similarly have been viewed as a result of the defense mechanism of displacement. From the psychodynamic perspective, anxiety usually reflects more basic, unresolved conflicts in intimate relationships or expression of anger.

More recent behavioral theories have emphasized the importance of two types of learning: classical conditioning and vicarious or observational learning. These theories have some empirical evidence to support them. In classical conditioning, a neutral stimulus acquires the ability to elicit a fear response after repeated pairings with a frightening (unconditioned) stimulus. In vicarious learning, fearful behavior is acquired by observing others' reactions to fear-inducing stimuli (Thorn et al., 1999). With general anxiety disorder, unpredictable positive and negative reinforcement is seen as leading to anxiety, especially because the person is unsure about whether avoidance behaviors are effective.

Cognitive factors, especially the way people interpret or think about stressful events, play a critical role in the etiology of anxiety (Barlow et al., 1996; Thorn et al., 1999). A decisive factor is the individual's perception, which can intensify or dampen the response. One of the most salient negative cognitions in anxiety is the sense of uncontrollability. It is typified by a state of helplessness due to a perceived inability to predict, control, or obtain desired results (Barlow et al., 1996). Negative cognitions are frequently found in individuals with anxiety (Ingram et al., 1998). Many modern psychological models of anxiety incorporate the role of individual vulnerability, which includes both genetic (Smoller & Tsuang, 1998) and acquired (Coplan et al., 1997) predispositions. There is evidence that women may ruminate more about distressing life events compared with men, suggesting that a cognitive risk factor may predispose them to higher rates of anxiety and depression (Nolen-Hoeksema et al., in press).

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[5] CRH may act as a neuromodulator, a neurotransmitter, or a neurohormone, depending on the pathway.

Treatment of Anxiety Disorders

The anxiety disorders are treated with some form of counseling or psychotherapy or pharmacotherapy, either singly or in combination (Barlow & Lehman, 1996; March et al., 1997; American Psychiatric Association, 1998; Kent et al., 1998).

Counseling and Psychotherapy

Anxiety disorders are responsive to counseling and to a wide variety of psychotherapies. More severe and persistent symptoms also may require pharmacotherapy (American Psychiatric Association, 1998).

During the past several decades, there has been increasing enthusiasm for more focused, time-limited therapies that address ways of coping with anxiety symptoms more directly rather than exploring unconscious conflicts or other personal vulnerabilities (Barlow & Lehman, 1996). These therapies typically emphasize cognitive and behavioral assessment and interventions.

The hallmarks of cognitive-behavioral therapies are evaluating apparent cause and effect relationships between thoughts, feelings, and behaviors, as well as implementing relatively straightforward strategies to lessen symptoms and reduce avoidant behavior (Barlow, 1988). A critical element of therapy is to increase exposure to the stimuli or situations that provoke anxiety. Without such therapeutic assistance, the sufferer typically withdraws from anxiety-inducing situations, inadvertently reinforcing avoidant or escape behavior.

The therapist provides reassurance that the feared situation is not deadly and introduces a plan to enhance mastery. This plan may include approaching the feared situation in a graduated or stepwise hierarchy or teaching the patient to use responses that dampen anxiety, such as deep muscle relaxation or coping. One fundamental principle is that prolonged exposure to a feared stimulus reliably decreases cognitive and physiologic symptoms of anxiety (Marks, 1969; Barlow, 1988). With such experience generally comes greater self-efficacy and a greater willingness to encounter other feared stimuli. For panic disorder, interoceptive training (a type of conditioning technique) and breathing exercises are often employed to help the sufferer become more capable of recognizing and coping with the social cues, antecedents, or early signs of a panic attack. Cognitive interventions are used to counteract the exaggerated or catastrophic thoughts that characterize anxiety. For treatment of obsessive-compulsive disorder, the strategy of response prevention must be added to exposure to ensure that compulsions are not performed (Barlow, 1988).

There is now extensive evidence that cognitive-behavioral therapies are useful treatments for a majority of patients with anxiety disorders (Chambless et al., 1998). Poorer outcomes are observed, however, in more complicated patient groups. With obsessive-compulsive disorder, approximately 20 to 25 percent of patients are unwilling to participate in therapy (March et al., 1997). Another major limitation of cognitive-behavioral therapies is not their effectiveness but, rather, the limited availability of skilled practitioners (Ballenger et al., 1998).

It is possible that more traditional forms of therapy based on psychodynamic or interpersonal theories of anxiety also may prove to be effective treatments (Shear, 1995). However, these therapies have not yet received extensive empirical support. As a result, more traditional therapies are generally deemphasized in evidence-based treatment guidelines for anxiety disorders.

Pharmacotherapy

The medications typically used to treat patients with anxiety disorders are benzodiazepines, antidepressants, and the novel compound buspirone (Lydiard et al., 1996). In light of increasing awareness of numerous neurochemical alterations in anxiety disorders, many new classes of drugs are likely to be developed, expressly targeting CRH and other neuroactive agents (Nemeroff, 1998).

Benzodiazepines

The benzodiazepines are a large class of relatively safe and widely prescribed medications that have rapid and profound antianxiety and sedative-hypnotic effects. The benzodiazepines are thought to exert their therapeutic effects by enhancing the inhibitory neurotransmitter systems utilizing GABA. Benzodiazepines bind to a site on the GABA receptor and act as receptor agonists (Perry et al., 1997). Benzodiazepines differ in terms of potency, pharmacokinetics (i.e., elimination half-life), and lipid solubility.

The four benzodiazepines currently widely prescribed for treatment of anxiety disorders are diazepam, lorazepam, clonazepam, and alprazolam. Each is now available in generic formulations (Davidson, 1998). Among these agents, alprazolam and lorazepam have shorter elimination half-lives—that is, are removed from the body more quickly—while diazepam and clonazepam have a long period of action (i.e., up to 24 hours). Diazepam also has multiple active metabolites, which increase the risk of “carryover” effects such as sedation and “hangover.” Benzodiazepines that undergo conjugation appear to have longer elimination time in women, and oral contraceptive can decrease clearance (Dawlans, 1995). Since Asians are more likely to metabolize diazepam more slowly, they may require lower doses to achieve the same blood concentrations as Caucasians (Lin et al., 1997).

Benzodiazepines have the potential for producing drug dependence (i.e., physiological or behavioral symptoms after discontinuation of use). Shorter acting compounds have somewhat greater liability because of more rapid and abrupt onset of withdrawal symptoms.

Because the benzodiazepines do not have strong antiobsessional effects, their use in obsessive-compulsive disorder and post-traumatic stress disorder is generally viewed as palliative (i.e., relieving, but not eliminating symptoms). Rather, obsessive-compulsive disorder and post-traumatic stress disorder are more effectively treated by antidepressants, especially the SSRIs (as discussed below). When effective, benzodiazepines should be tapered after several months of use, although there is a substantial risk of relapse. Many clinicians favor a combined treatment approach for panic disorder and generalized anxiety disorder, in which benzodiazepines are used acutely in tandem with an antidepressant. The benzodiazepines are subsequently tapered as the antidepressant’s therapeutic effects begin to emerge (American Psychiatric Association, 1998).

Antidepressants

Most antidepressant medications have substantial antianxiety and antipanic effects in addition to their antidepressant action (Kent et al., 1998). Moreover, a large number of antidepressants have antiobsessional effects (Perry et al., 1997). The observation that the tricyclic antidepressant imipramine had a different anxiolytic profile than diazepam helped to differentiate panic disorder from generalized anxiety disorder and, subsequently, social phobia.

Clomipramine, a tricyclic antidepressant (TCA) with relatively potent reuptake inhibitory effects on serotonin (5-HT) neurons, subsequently was found to be the only TCA to have specific antiobsessional effects (March et al., 1997). The importance of this effect on 5-HT was highlighted when the SSRIs became available. By the late 1990s, it became clear that all of the SSRIs have antiobsessional effects (Greist et al., 1995; Kent et al., 1998).

Current practice guidelines rank the TCAs below the SSRIs for treatment of anxiety disorders because of the SSRIs’ more favorable tolerability and safety profiles (March et al., 1997; American Psychiatric Association, 1998; Ballenger et al., 1998;). Nevertheless, there are patients who respond to the TCAs after failing to respond to one or more of the newer agents. Similarly, although relatively rarely used, the monoamine oxidate inhibitors (MAOIs) have significant antiobsessional, antipanic, and anxiolytic effects (Sheehan et al., 1980; American Psychiatric Association, 1998). In the United States, the MAOIs phenelzine, tranylcypromine, and isocarboxazid (which has not been consistently marketed this decade) are seldom used unless simpler medication strategies have failed (American Psychiatric Association, 1998).

The five drugs within the SSRI class—fluoxetine, sertraline, paroxetine, fluvoxamine, and citalopram—have emerged as the preferred type of antidepressant for treatment of anxiety disorders (Westenberg, 1996; Kent et al., 1998). In addition to well-established efficacy in obsessive-compulsive disorder, there is convincing and growing evidence of antipanic and broader anxiolytic effects (American Psychiatric Association, 1998; Kent et al., 1998). Treatment of panic disorder often requires lower initial doses and slower upward titration. By contrast, treatment for obsessive-compulsive disorder ultimately may entail higher doses (for example, 60 or 80 mg/day of fluoxetine or 200 mg per day of sertraline) and longer durations to achieve desired outcomes (March et al., 1997). As all of the SSRIs are currently protected by patents, there are no generic forms yet available. This adds to the direct costs of treatment. Cost may be offset indirectly, however, by virtue of need for fewer treatment visits and fewer concomitant medications, and cost likely will abate when these agents begin to lose patent protection in a few years.

Other newer antidepressants, including venlafaxine, nefazodone, and mirtazapine, also may have significant antianxiety effects, for which clinical trials are under way (March et al., 1997; American Psychiatric Association, 1998). Paroxetine has been approved by the Food and Drug Administration (FDA) for social phobia, and sertraline is being developed for post-traumatic stress disorder. Nefazodone, which also is being studied in post-traumatic stress disorder, and mirtazapine may possess lower levels of sexual side effects, a problem that complicates longer term treatment with SSRIs, venlafaxine, TCAs, and MAOIs (Baldwin & Birtwistle, 1998).

When effective in treating anxiety, antidepressants should be maintained for at least 4 to 6 months, then tapered slowly to avoid discontinuation-emergent activation of anxiety symptoms (March et al., 1997; American Psychiatric Association, 1998; Ballenger et al., 1998). Although less extensively researched than depression, it is likely that many patients with anxiety disorders may warrant longer term, indefinite treatment to prevent relapse or chronicity.

Buspirone

This azopyrine compound is a relatively selective 5-HT_{1A} partial agonist (Stahl, 1996). It was approved by the FDA in the mid-1980s as an anxiolytic. However, unlike the benzodiazepines, buspirone is not habit forming and has no abuse potential. Buspirone also has a safety profile comparable to the SSRIs, and it is significantly better tolerated than the TCAs.

Buspirone does not block panic attacks, and it is not efficacious as a primary treatment of obsessive-compulsive disorder or post-traumatic stress disorder (Stahl, 1996). Buspirone is most useful for treatment of generalized anxiety disorder, and it is now frequently used as an adjunct to SSRIs (Lydiard et al., 1996). Buspirone takes 4 to 6 weeks to exert therapeutic effects, like antidepressants, and it has little value for patients when taken on an "as needed" basis.

Combinations of Psychotherapy and Pharmacotherapy

Some patients with anxiety disorders may benefit from both psychotherapy and pharmacotherapy treatment modalities, either combined or used in sequence (March et al., 1997; American Psychiatric Association, 1998). Drawing from the experiences of depression researchers, it seems likely that such combinations are not uniformly necessary and are probably more cost-effective when reserved for patients with more complex, complicated, severe, or comorbid disorders. The benefits of multimodal therapies for anxiety need further study.

Mood Disorders

In 1 year, about 7 percent of Americans suffer from mood disorders, a cluster of mental disorders best recognized by depression or mania (Table 4-1). Mood disorders are outside the bounds of normal fluctuations from sadness to elation. They have potentially severe consequences for morbidity and mortality.

This section covers four mood disorders. As the predominant mood disorder, major depressive disorder (also known as unipolar major depression), garners the greatest attention. It is twice more common in women than in men, a gender difference that is discussed later in this section. The other mood disorders covered below are bipolar disorder, dysthymia, and cyclothymia.

Mood disorders rank among the top 10 causes of worldwide disability (Murray & Lopez, 1996). Unipolar major depression ranks first, and bipolar disorder ranks in the top 10. Moreover, disability and suffering are not limited to the patient. Spouses, children, parents, siblings, and friends experience frustration, guilt, anger, financial hardship, and, on occasion, physical abuse in their attempts to assuage or cope with the depressed person's suffering. Women between the ages of 18 and 45 comprise the majority of those with major depression (Regier et al., 1993).

Depression also has a deleterious impact on the economy, both in diminished productivity and in use of health care resources (Greenberg et al., 1993). In the workplace, depression is a leading cause of absenteeism and diminished productivity. Although only a minority seek professional help to relieve a mood disorder, depressed people are significantly more likely than others to visit a physician for some other reason. Depression-related visits to physicians thus account for a large portion of health care expenditures. Seeking another or a less stigmatized explanation for their difficulties, some depressed patients undergo extensive and expensive diagnostic procedures and then get treated for various other complaints while the mood disorder goes undiagnosed and untreated (Wells et al., 1989).

Complications and Comorbidities

Suicide is the most dreaded complication of major depressive disorders. About 10 to 15 percent of patients formerly hospitalized with depression commit suicide (Angst et al., 1999). Major depressive disorders account for about 20 to 35 percent of all deaths by suicide (Angst et al., 1999). Completed suicide is more common among those with more severe and/or psychotic symptoms, with late onset, with co-existing mental and addictive disorders (Angst et al., 1999), as well as among those who have experienced stressful life events, who have medical illnesses, and who have a family history of suicidal behavior (Blumenthal, 1988). In the United States, men complete suicide four times as often as women; women attempt suicide four times as frequently as do men (Blumenthal, 1988). Recognizing the magnitude of this public health problem, the Surgeon General issued a *Call to Action on Suicide* in 1999 (see Figure 4-1). Individuals with depression also face an increased risk of death from coronary artery disease (Glassman & Shapiro, 1998).

Mood disorders often coexist, or are *comorbid*, with other mental and somatic disorders. Anxiety is commonly comorbid with major depression. About one-half of those with a primary diagnosis of major depression also have an anxiety disorder (Barbee, 1998; Regier et al., 1998). The comorbidity of anxiety and depression is so pronounced that it has led to theories of similar etiologies, which are discussed below. Substance use disorders are found in 24 to 40 percent of individuals with mood disorders in the United States (Merikangas et al., 1998). Without treatment, substance abuse worsens the course of mood disorders. Other common comorbidities include personality disorders (DSM-IV) and medical illness, especially chronic conditions such as hypertension and arthritis. People with depression have a high prevalence (65 to 71 percent) of any of eight common chronic medical conditions (Wells et al., 1991). The mood disorders also may alter or "scar" personality development.

Figure 4-1. Surgeon General's Call to Action to Prevent Suicide—1999

- Suicide is a serious public health problem
    - 31,000 suicides in 1996
    - 500,000 people visit emergency rooms due to attempted suicide
- Suicide rate declined from 12.1 per 100,000 in 1976 to 10.8 per 100,000 in 1996
    - Rate in adolescents and young adults almost tripled since 1952
    - Rate is 50 percent higher than the homicide rate
- National Strategy for Suicide Prevention: AIM
    - Awareness: promote public awareness of suicide as a public health problem
    - Intervention: enhance services and programs
    - Methodology: advance the science of suicide prevention
- Risk factors
    - Male gender
    - Mental disorders, particularly depression and substance abuse
    - Prior suicide attempts
    - Unwillingness to seek help because of stigma
    - Barriers to accessing mental health treatment
    - Stressful life event/loss
    - Easy access to lethal methods such as guns
- Protective factors
    - Effective and appropriate clinical care for underlying disorders
    - Easy access to care
    - Support from family, community, and health and mental health care staff

Clinical Depression Versus Normal Sadness

People have been plagued by disorders of mood for at least as long as they have been able to record their experiences. One of the earliest terms for depression, "melancholy," literally meaning "black bile," dates back to Hippocrates. Since antiquity, dysphoric states outside the range of normal sadness or grief have been recognized, but only within the past 40 years or so have researchers had the means to study the changes in cognition and brain functioning that are associated with severe depressive states.

At some time or another, virtually all adult human beings will experience a tragic or unexpected loss, romantic heartbreak, or a serious setback and times of profound sadness, grief, or distress. Indeed, something is awry if the usual expressions of sadness do not accompany such situations so common to the human condition—death of a loved one, severe illness, prolonged disability, loss of employment or social status, or a child's difficulties, for example.

What is now called major depressive disorder, however, differs both *quantitatively* and *qualitatively* from normal sadness or grief. Normal states of dysphoria (a negative or aversive mood state) are typically less pervasive and generally run a more time-limited course. Moreover, some of the symptoms of severe depression, such as anhedonia (the inability to experience pleasure), hopelessness, and loss of mood reactivity (the ability to feel a mood uplift in response to something positive) only rarely accompany "normal" sadness. Suicidal thoughts and psychotic symptoms such as delusions or hallucinations virtually always signify a pathological state.

Nevertheless, many other symptoms commonly associated with depression are experienced during times of stress or bereavement. Among them are sleep disturbances, changes in appetite, poor concentration, and ruminations on sad thoughts and feelings. When a person suffering such distress seeks help, the diagnostician's task is to differentiate the normal from the pathologic and, when appropriate, to recommend treatment.

Assessment: Diagnosis and Syndrome Severity

The criteria for diagnosing major depressive episode, dysthymia, mania, and cyclothymia are presented in Tables 4-2 through 4-5. Mania is an essential feature of bipolar disorder, which is marked by episodes of mania or mixed episodes of mania and depression. The reliability of the diagnostic criteria for major depressive disorder and bipolar disorder is impressive, with greater than 90 percent agreement reached by independent evaluators (DSM-IV).

Major Depressive Disorder

Major depressive disorder features one or more major depressive episodes (see Table 4-2), each of which lasts at least 2 weeks (DSM-IV). Since these episodes are also characteristic of bipolar disorder, the term "major[6] depression" refers to both major depressive disorder and the depression of bipolar disorder.

The cardinal symptoms of major depressive disorder are depressed mood and loss of interest or pleasure. Other symptoms vary enormously. For example, insomnia and weight loss are considered to be classic signs, even though many depressed patients gain weight and sleep excessively. Such heterogeneity is partly dealt with by the use of diagnostic subtypes (or course modifiers) with differing presentations and prevalence. For example, a more severe depressive syndrome characterized by a constellation of classical signs and symptoms, called melancholia, is more common among older than among younger people, as are depressions characterized by psychotic features (i.e., delusions and hallucinations) (DSM-IV). In fact, the presentation of psychotic features without concomitant melancholia should always raise suspicion about the accuracy of the diagnosis (vis-à-vis schizophrenia or a related psychotic disorder). The so-called *reversed vegetative symptoms* (oversleeping, overeating, and weight gain) may be more prevalent in women than men (Nemeroff, 1992). Anxiety symptoms such as panic attacks, phobias, and obsessions also are not uncommon.

When untreated, a major depressive episode may last, on average, about 9 months. Eighty to 90 percent of individuals will remit within 2 years of the first episode (Kapur & Mann, 1992). Thereafter, at least 50 percent of depressions will recur, and after three or more episodes the odds of recurrence within 3 years increases to 70 to 80 percent if the patient has not had preventive treatment (Thase & Sullivan, 1995). Thus, for many, an initial episode of major depression will evolve over time into the more recurrent illness sometimes referred to as unipolar major depression (Thase & Sullivan, 1995). Each new episode also confers new risks of chronicity, disability, and suicide.

Dysthymia

Dysthymia is a chronic form of depression. Its early onset and unrelenting, "smoldering" course are among the features that distinguish it from major depressive disorder (DSM-IV). Dysthymia becomes so intertwined with a person's self-concept or personality that the individual may be misidentified as "neurotic" (resulting from unresolved early conflicts expressed through unconscious personality defenses or characterologic disorders) (Akiskal, 1985). Indeed, the onset of dysthymia in childhood or adolescence undoubtedly affects personality development and coping styles, particularly prompting passive, avoidant, and dependent "traits." To avoid the pejorative connotations associated with the terms "neurotic" and "characterologic," the term "dysthymia" is used in DSM-IV as a descriptive, or atheoretical, diagnosis for a chronic form of depression (see Table 4-3) (DSM-IV). Affecting about 2 percent of the adult population in 1 year, dysthymia is defined by its subsyndromal nature (i.e., fewer than the five persistent symptoms required to diagnose a major depressive episode) and a protracted duration of at least 2 years for adults and 1 year for children. Like other early-onset disorders, dysthymic disorder is associated with higher rates of comorbid substance abuse. People with dysthymia also are susceptible to major depression. When this occurs, their illness is sometimes referred to as "double depression," that is, the combination of dysthymia and major depression (Keller & Shapiro, 1982). Unlike the superimposed major depressive episode, however, the underlying dysthymia seldom remits spontaneously. Women are twice as likely to be diagnosed with dysthymia as men (Robins & Regier, 1991).

Bipolar Disorder

Bipolar disorder is a recurrent mood disorder featuring one or more episodes of mania or mixed episodes of mania and depression (DSM-IV; Goodwin & Jamison,

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[6] The adjective "major" before the word "depression" denotes the number of symptoms required for the diagnosis, as distinct, from a proposed new category of "minor depression," which requires fewer symptoms (see Chapter 5).

Table 4-2. DSM-IV criteria for major depressive episode

A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.

Note: Do not include symptoms that are clearly due to a general medical condition, or mood-incongruent delusions or hallucinations.

(1) depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful). **Note:** In children and adolescents, can be irritable mood.
(2) markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others).
(3) significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day. **Note:** In children, consider failure to make expected weight gains.
(4) insomnia or hypersomnia nearly every day.
(5) psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings or restlessness or being slowed down).
(6) fatigue or loss of energy nearly every day.
(7) feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
(8) diminished ability to think or concentrate, or indecisiveness, nearly every day (either subjective account or as observed by others).
(9) recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

B. The symptoms do not meet criteria for a mixed episode.

C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

D. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).

E. The symptoms are not better accounted for by bereavement, i.e., after the loss of a loved one; the symptoms persist for longer than 2 months or are characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation.

Table 4-3. DSM-IV diagnostic criteria for Dysthymic Disorder

A. Depressed mood for most of the day, for more days than not, as indicated either by subjective account or observation by others, for at least 2 years. **Note:** In children and adolescents, mood can be irritable and duration must be at least 1 year.

B. Presence, while depressed, of two (or more) of the following:

(1) poor appetite or overeating
(2) insomnia or hypersomnia
(3) low energy or fatigue
(4) low self-esteem
(5) poor concentration or difficulty making decisions
(6) feelings of hopelessness

C. During the 2-year period (1 year for children or adolescents) of the disturbance, the person has never been without the symptoms in Criteria A and B for more than 2 months at a time.

D. No major depressive episode has been present during the first 2 years of the disturbance (1 year for children and adolescents); i.e., the disturbance is not better accounted for by chronic major depressive disorder, or major depressive disorder, in partial remission.

Note: There may have been a previous major depressive episode provided there was a full remission (no significant signs or symptoms for 2 months) before development of the dysthymic disorder. In addition, after the initial 2 years (1 year in children or adolescents) of dysthymic disorder, there may be superimposed episodes of major depressive disorder, in which case both diagnoses may be given when the criteria are met for a major depressive episode.

E. There has never been a manic episode, a mixed episode, or a hypomanic episode, and criteria have never been met for cyclothymic disorder.

F. The disturbance does not occur exclusively during the course of a chronic psychotic disorder, such as schizophrenia or delusional disorder.

G. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).

H. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

1990). Bipolar disorder[7] is distinct from major depressive disorder by virtue of a history of manic or hypomanic (milder and not psychotic) episodes. Other differences concern the nature of depression in bipolar disorder. Its depressive episodes are typically associated with an earlier age at onset, a greater likelihood of reversed vegetative symptoms, more frequent episodes or recurrences, and a higher familial prevalence (DSM-IV; Goodwin & Jamison, 1990). Another noteworthy difference between bipolar and nonbipolar groups is the differential therapeutic effect of lithium salts, which are more helpful for bipolar disorder (Goodwin & Jamison, 1990).

Mania is derived from a French word that literally means crazed or frenzied. The mood disturbance can range from pure euphoria or elation to irritability to a labile admixture that also includes dysphoria (Table 4-4). Thought content is usually grandiose but also can be paranoid. Grandiosity usually takes the form both of overvalued ideas (e.g., "My book is the best one ever written") and of frank delusions (e.g., "I have radio transmitters implanted in my head and the Martians are monitoring my thoughts.") Auditory and visual hallucinations complicate more severe episodes. Speed of thought increases, and ideas typically race through the manic person's consciousness. Nevertheless, distractibility and poor concentration commonly impair implementation. Judgment also can be severely compromised; spending sprees, offensive or disinhibited behavior, and promiscuity or other objectively reckless behaviors are commonplace. Subjective energy, libido, and activity typically increase but a perceived reduced need for sleep can sap physical reserves. Sleep deprivation also can exacerbate cognitive difficulties and contribute to development of catatonia or a florid, confusional state known as delirious mania. If the manic patient is delirious, paranoid, or catatonic, the behavior is difficult to distinguish from that of a schizophrenic patient. Clinicians are prone to misdiagnose mania as schizophrenia in African Americans (Bell & Mehta, 1981). Most people with bipolar disorder have a history of remission and at least satisfactory functioning before onset of the index episode of illness.

In DSM-IV, bipolar depressions are divided into type I (prior mania) and type II (prior hypomanic episodes only). About 1.1 percent of the adult population suffers from the type I form, and 0.6 percent from the type II form (Goodwin & Jamison, 1990; Kessler et al., 1994) (Table 4-5). Episodes of mania occur, on average, every 2 to 4 years, although accelerated mood cycles can occur annually or even more frequently. The type I form of bipolar disorder is about equally common in men and women, unlike major depressive disorder, which is more common in women.

Hypomania, as suggested above, is the subsyndromal counterpart of mania (DSM-IV; Goodwin & Jamison, 1990). By definition, an episode of hypomania is never psychotic nor are hypomanic episodes associated with marked impairments in judgment or performance. In fact, some people with bipolar disorder long for the productive energy and heightened creativity of the hypomanic phase.

Hypomania can be a transitional state (i.e., early in an episode of mania), although at least 50 percent of those who have hypomanic episodes never become manic (Goodwin & Jamison, 1990). Whereas a majority have a history of major depressive episodes (bipolar type II disorder), others become hypomanic only during antidepressant treatment (Goodwin & Jamison, 1990). Despite the relatively mild nature of hypomania, the prognosis for patients with bipolar type II disorder is poorer than that for recurrent (unipolar) major depression, and there is some evidence that the risk of rapid cycling (four or more episodes each year) is greater than with bipolar type I (Coryell et al., 1992). Women are at higher risk for rapid cycling bipolar disorder than men (Coryell et al., 1992). Women with bipolar disorder are also at increased risk for an episode during pregnancy and the months following childbirth (Blehar et al., 1998).

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[7] Bipolar disorder is also known as bipolar affective disorder and manic depression.

Table 4-4. DSM-IV criteria for manic episode

A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood, lasting at least 1 week (or any duration if hospitalization is necessary).

B. During the period of mood disturbance, three (or more) of the following symptoms have persisted (four if the mood is only irritable) and have been present to a significant degree:

(1) inflated self-esteem or grandiosity

(2) decreased need for sleep (e.g., feels rested after only 3 hours of sleep)

(3) more talkative than usual or pressure to keep talking

(4) flight of ideas or subjective experience that thoughts are racing

(5) distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli)

(6) increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation

(7) excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)

C. The symptoms do not meet criteria for a mixed episode.

D. The mood disturbance is sufficiently severe to cause marked impairment in occupational functioning or in usual social activities or relationships with others, or to necessitate hospitalization to prevent harm to self or others, or there are psychotic features.

E. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication, or other treatment) or general medical condition (e.g., hyperthyroidism).

Note: Manic-like episodes that are clearly caused by somatic antidepressant treatment (e.g., medication, electroconvulsive therapy, light therapy) should not count toward a diagnosis of bipolar I disorder.

Table 4-5. DSM-IV diagnostic criteria for Cyclothymic Disorder

A. For at least 2 years, the presence of numerous periods with hypomanic symptoms and numerous periods with depressive symptoms that do not meet criteria for a major depressive episode. **Note:** In children and adolescents, the duration must be at least 1 year.

B. During the above 2-year period (1 year in children and adolescents), the person has not been without the symptoms in Criterion A for more than 2 months at a time.

C. No major depressive episode, manic episode, or mixed episode has been present during the first 2 years of the disturbance.

Note: After the initial 2 years (1 year in children and adolescents) of cyclothymic disorder, there may be superimposed manic or mixed episodes (in which case both bipolar I disorder and cyclothymic disorder may be diagnosed) or major depressive episodes (in which case both bipolar II disorder and cyclothymic disorder may be diagnosed).

D. The symptoms in Criterion A are not better accounted for by schizoaffective disorder and are not superimposed on schizophrenia, schizophreniform disorder, delusional disorder, or psychotic disorder not otherwise specified.

E. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hyperthyroidism).

F. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Cyclothymia

Cyclothymia is marked by manic and depressive states, yet neither are of sufficient intensity nor duration to merit a diagnosis of bipolar disorder or major depressive disorder. The diagnosis of cyclothymia is appropriate if there is a history of hypomania, but no prior episodes of mania or major depression (Table 4-5). Longitudinal followup studies indicate that the risk of bipolar disorder developing in patients with cyclothymia is about 33 percent; although 33 times greater than that for the general population, this rate of risk still is too low to justify viewing cyclothymia as merely an early manifestation of bipolar type I disorder (Howland & Thase, 1993).

Differential Diagnosis

Mood disorders are sometimes caused by general medical conditions or medications. Classic examples include the depressive syndromes associated with dominant hemispheric strokes, hypothyroidism, Cushing's disease, and pancreatic cancer (DSM-IV). Among medications associated with depression, antihypertensives and oral contraceptives are the most frequent examples. Transient depressive syndromes are also common during withdrawal from alcohol and various other drugs of abuse. Mania is not uncommon during high-dose systemic therapy with glucocorticoids and has been associated with intoxication by stimulant and sympathomimetic drugs and with central nervous system (CNS) lupus, CNS human immunodeficiency viral (HIV) infections, and nondominant hemispheric strokes or tumors. Together, mood disorders due to known physiological or medical causes may account for as many as 5 to 15 percent of all treated cases (Quitkin et al., 1993b). They often go unrecognized until after standard therapies have failed.

A challenge to diagnosticians is to balance their search for relatively uncommon disorders with their sensitivity to aspects of the medical history or review of symptoms that might have etiologic significance. For example, the onset of a depressive episode a few weeks or months after the patient has begun taking a new blood-pressure medication should raise the physician's index of suspicion. Ultimately, occult or covert medical illnesses must always be considered when an apparently clear-cut case of a mood disorder is refractory to standard treatments (Depression Guideline Panel, 1993). Cultural influences on the manifestation and diagnosis of depression are also important for the diagnostician to identify (DSM-IV). As discussed in Chapter 2, somatization is especially prevalent in individuals from ethnic minority backgrounds (Lu et al., 1995). Somatization is the expression of mental distress in terms of physical suffering.

Etiology of Mood Disorders

The etiology of depression, the mood disorder most frequently studied, is far from ideally understood. Many cases of depression are triggered by stressful life events, yet not everyone becomes depressed under such circumstances. The intensity and duration of these events, as well as each individual's genetic endowment, coping skills and reaction, and social support network contribute to the likelihood of depression. That is why depression and many other mental disorders are broadly described as the product of a complex interaction between biological and psychosocial factors (see Chapter 2). The relative importance of biological and psychosocial factors may vary across individuals and across different types of depression.

This section of the chapter describes the biological, genetic, and psychosocial factors—such as cognition, personality, and gender—that correlate with, or predispose to, depression. The discussion of genetic factors also incorporates the latest findings about bipolar disorder. Genes are implicated even more strongly in bipolar disorder than they are in major depression, galvanizing a worldwide search to identify chromosomal regions where genes may be located and ultimately to pinpoint the genes themselves (NIMH, 1998).

Biologic Factors in Depression

Much of the scientific effort expended over the past 40 years on the study of depression has been devoted to the search for biologic alterations in brain function. From the beginning, it has been recognized that the clinical heterogeneity of depression disorders may preclude the possibility of finding a single defect. Researchers have detected abnormal concentrations of many neurotransmitters and their metabolites in urine, plasma, and cerebrospinal fluid in subgroups of patients (Thase & Howland, 1995); dysregulation of the HPA axis (Thase & Howland, 1995); elevated levels of corticotropin-releasing factor (Nemeroff, 1992, 1998; Mitchell, 1998); and, most recently, abnormalities in second messenger systems and neuroimaging (Drevets, 1998; Rush et al., 1998, Steffens & Krishnan, 1998). Much current research focuses on how *the biological abnormalities* interrelate, how they correlate with behavioral and emotional patterns that seem to distinguish one subcategory of major depression from another, and how they respond to diverse forms of therapy.

In the search for biological changes with depression, it must be understood that *a biological abnormality* reliably associated with depression may not actually be a causal factor. For example, a biologic alteration could be a consequence of sleep deprivation or weight loss. *Any biological abnormality* found in conjunction with any mental disorder may be a cause, a correlate, or a consequence, as discussed in Chapter 2. What drives research is the determination to find which of *the biological abnormalities* in depression are true causes, especially ones that might be detectable and treatable *before* the onset of clinical symptoms.

Monoamine Hypothesis

For many years the prevailing hypothesis was that depression was caused by an absolute or relative deficiency of monoamine[8] transmitters in the brain. This line of research was bolstered by the discovery many years ago that reserpine, a medication for hypertension, inadvertently caused depression. It did so by depleting the brain of both serotonin and the three principal catecholamines (dopamine, norepinephrine, and epinephrine). Such findings led to the "catecholamine hypothesis" and the "indoleamine (i.e., serotonin) hypothesis," which in due course led to an integrated "monoamine hypothesis" (Thase & Howland, 1995).

After more than 30 years of research, however, the monoamine hypothesis has been found insufficient to explain the complex etiology of depression. One problem is that many other neurotransmitter systems are altered in depression, including GABA and acetylcholine (Rush et al., 1998). Another problem is that improvement of monoamine neurotransmission with medications and lifting of the clinical signs of depression do not prove that depression actually is caused by defective monoamine neurotransmission. For example, diuretic medications do not specifically correct the physiological defect underlying congestive heart failure, but they do treat its symptoms. Neither impairment of monoamine synthesis, nor excessive degradation of monoamines, is consistently present in association with depression; monoamine precursors do not have consistent antidepressant effects, and a definite temporal lag exists between the quick elevation in monoamine levels and the symptom relief that does not emerge until weeks later (Duman et al., 1997). To account for these discrepancies, one new model of depression proposes that depression results from reductions in neurotrophic factors that are necessary for the survival and function of particular neurons, especially those found in the hippocampus (Duman et al., 1997).

Despite the problems with the hypothesis that monoamine depletion is the *primary* cause of depression, monoamine impairment is certainly one of the manifestations, or correlates, of depression. Therefore, the monoamine hypothesis remains important for treatment purposes. Many currently available pharmacotherapies that relieve depression or cause mania, or both, enhance monoamine activity. One of the foremost classes of drugs for depression, SSRIs, for example, boost the level of serotonin in the brain.

Evolving Views of Depression

An important shortcoming of the monoamine hypothesis was its inattention to the psychosocial risk factors that influence the onset and persistence of depressive episodes. The nature and interpretation of, and the response to, stress clearly have important causal roles in depression. The following discussion illustrates ongoing work aimed at understanding the pathophysiology of depression. While incomplete, it offers a coherent integration of the biological, psychological, and social factors that have long been associated clinically with this disorder.

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[8] Monoamine neurotransmitters are a chemical class that includes catecholamines (norepinephrine, epinephrine, dopamine) and indoleamines (serotonin).

Many decades ago, Hans Selye demonstrated the damaging effects of chronic stress on the HPA axis, the gastrointestinal tract, and the immune system of rats: adrenal hypertrophy, gastric ulceration, and involution of the thymus and lymph nodes (Selye, 1956). Since that time, researchers have provided ample evidence that brain function, and perhaps even anatomic structure, can be influenced by stress, interpretation of stress, and learning (Weiss, 1991; Sapolsky, 1996; McEwen, 1998). Much current research has been directed at stress, the HPA axis, and CRH in the genesis of depression.

Depression can be the outcome of severe and prolonged stress (Brown et al., 1994; Frank et al., 1994; Ingram et al., 1998). The acute stress response is characterized by heightened arousal—the fight-or-flight response—that entails mobilization of the sympathetic nervous system and the HPA axis (see Etiology of Anxiety). Many aspects of the acute stress response are exaggerated, persistent, or dysregulated in depression (Thase & Howland, 1995). Increased activity in the HPA axis in depression is viewed as the "most venerable finding in all of biological psychiatry" (Nemeroff, 1998).

Increased activity of the HPA axis, however, may be secondary to more primary causes, as was the problem with the monoamine hypothesis of depression. For this reason, much attention has been focused on CRH, which is hypersecreted in depression (Nemeroff, 1992, 1998). CRH is the neuropeptide that is released by the hypothalamus to activate the pituitary in the acute stress response. Yet there are many other sources of CRH in the brain.

CRH injections into the brain of laboratory animals produce the signs and symptoms found in depressed patients, including decreased appetite and weight loss, decreased sexual behavior and sleep, and other changes (Sullivan et al., 1998). Furthermore, CRH is found in higher concentrations in the cerebrospinal fluid of depressed patients (Nemeroff, 1998). In autopsy studies of depressed patients, CRH gene expression is elevated, and there are greater numbers of hypothalamic neurons that express CRH (Nemeroff, 1998). These findings have ignited research to uncover how CRH expression in the hypothalamus is regulated, especially by other brain centers such as the hippocampus (Mitchell, 1998). The hippocampus exerts control over the HPA axis through feedback inhibition (Jacobson & Sapolsky, 1991). Shedding light on the regulation of CRH is expected to hold dividends for understanding both anxiety and depression.

Anxiety and Depression

Anxiety and depression frequently coexist, so much so that patients with combinations of anxiety and depression are the rule rather than the exception (Barbee, 1998). And many of the medications used to treat either one are often used to treat the other. Why are anxiety and depression so interrelated?

Clues to answering this question are expected to come from similarities in antecedents, correlates, and consequences of each condition. Certainly, stressful events are frequent, although not universal, antecedents. Overlapping biochemical correlates are found, most notably, an elevation in CRH (Arborelius et al., 1999). Interestingly, one new line of research finds that long-term consequences of anxiety and depression are evident at the same anatomical site—the hippocampus. Human imaging studies of the hippocampus revealed it to have smaller volume in patients with post-traumatic stress disorder (McEwen, 1998) and in patients with recurrent depression (Sheline, 1996). In the latter study, the degree of volume reduction was correlated with the duration of major depression. In both conditions, excess glucocorticoid exposure was thought to be the culprit in inducing the atrophy of hippocampal neurons. But the complete chain of events leading up to and following the hippocampal damage is not yet known.

Psychosocial and Genetic Factors in Depression

If stressful events are the proximate causes of most cases of depression, then why is it that not all people become depressed in the face of stressful events? The answer appears to be that social, psychological, and genetic factors act together to predispose to, or protect against, depression. This section first discusses stressful life events, followed by a discussion of the factors that shape our responses to them.

Stressful Life Events

Adult life can be rife with stressful events, as noted earlier, and although not all people with depression can point to some precipitating event, many episodes of depression are associated with some sort of acute or chronic adversity (Brown et al., 1994; Frank et al., 1994; Ingram et al., 1998).

The death of a loved one is viewed as one of the most powerful life stressors. The grief that ensues is a universal experience. Common symptoms associated with bereavement include crying spells, appetite and weight loss, and insomnia. Grief, in fact, has such emotional impact that the diagnosis of depressive disorder should not be made unless there are definite complications such as incapacity, psychosis, or suicidal thoughts.

The compelling impact of past parental neglect, physical and sexual abuse, and other forms of maltreatment on both adult emotional well-being and brain function is now firmly established for depression. Early disruption of attachment bonds can lead to enduring problems in developing and maintaining interpersonal relationships and problems with depression and anxiety. Research in animals bears this out as well. In both rodents and primates, maternal deprivation stresses young animals, and a pattern of repeated, severe, early trauma from maternal deprivation may predispose an animal to a lifetime of overreactivity to stress (Plotsky et al., 1995). Conversely, early experience with mild, nontraumatic stressors (such as gentle handling) may help to protect or "immunize" animals against more pathologic responses to subsequent severe stress.

Cognitive Factors

According to cognitive theories of depression, how individuals view and interpret stressful events contributes to whether or not they become depressed. One prominent theory of depression stems from studies of learned helplessness in animals. The theory posits that depression arises from a cognitive state of helplessness and entrapment (Seligman, 1991). The theory was predicated on experiments in which animals were trained in an enclosure in which shocks were unavoidable and inescapable, regardless of avoidance measures that animals attempted. When they later were placed in enclosures in which evasive action could have succeeded, the animals were inactive, immobile, and unable to learn avoidance maneuvers. The earlier experience engendered a behavioral state of helplessness, one in which actions were seen as ineffectual.

In humans there is now ample evidence that the impact of a stressor is moderated by the personal meaning of the event or situation. In other words, the critical factor is the person's interpretation of the stressor's potential impact. Thus, an event interpreted as a threat or danger elicits a nonspecific stress response, and an event interpreted as a loss (of either an attachment bond or a sense of competence) elicits more grieflike depressive responses.

Heightened vulnerability to depression is linked to a constellation of cognitive patterns that predispose to distorted interpretations of a stressful event (Ingram et al., 1998). For example, a romantic breakup will trigger a much stronger emotional response if the affected person believes, "I am incomplete and empty without her love," or "I will never find another who makes me feel the way he does." The cognitive patterns associated with distorted interpretation of stress include relatively harsh or rigid beliefs or attitudes about the importance of romantic love or achievement (again, the centrality of love and work) as well as the tendency to attribute three specific qualities to adverse events: (1) global impact–"This event will have a *big* effect on me"; (2) internality–"*I* should have done something to prevent this," or "This is *my* fault"; and (3) irreversibility–"I'll never be able to recover from this."

According to a recent model of cognitive vulnerability to depression, negative cognitions by themselves are not sufficient to engender depression. This model postulates, on the basis of previously gathered empirical evidence, that interactions between negative cognitions and mildly depressed mood are important in the etiology and recurrences of depression. Patterns or styles of thinking stem from prior negative experiences. When they are activated by adverse life events and a mildly depressed mood, a downward spiral ensues, leading to depression (Ingram et al., 1998).

Temperament and Personality

Responses to life events also can be linked to personality (Hirschfeld & Shea, 1992). Personality may be understood in terms of one's attitudes and beliefs as well as more enduring neurobehavioral predispositions referred to as temperaments. The study of personality and temperament is gaining momentum. Neuroticism (a temperament discussed earlier in this chapter) predisposes to anxiety and depression (Clark et al., 1994). Having an easy-going temperament, on the other hand, protects against depression (IOM, 1994). Further, those with severe personality disorder are particularly likely to have a history of early adversity or maltreatment (Browne & Finkelhor, 1986).

Temperaments are not destiny, however. Parental influences and individual life experiences may determine whether a shy child remains vulnerable or becomes a healthy, albeit somewhat reserved, adult. In adults, several constellations of personality traits are associated with mood disorders: avoidance, dependence, and traits such as reactivity and impulsivity (Hirschfeld & Shea, 1992). People who have such personality traits not only cope less effectively with stressors but also tend to provoke or elicit adversity. A personality disorder or temperamental disturbance may mediate the relationship between stress and depression.

Gender

Major depressive disorder and dysthymia are more prevalent among women than men, as noted earlier. This difference appears in different cultures throughout the world (Weissman et al., 1993). Understanding the gender-related difference is complex and likely related to the interaction of biological and psychosocial factors (Blumenthal, 1994a), including differences in stressful life events as well as to personality (Nolen-Hoeksema et al., in press).

Keys to understanding the sex-related difference in rates in the United States may be found in two types of epidemiologic findings: (1) there are no sex-related differences in rates of bipolar disorder (type I) (NIMH, 1998) and, (2) within the agrarian culture of the Old Order Amish of Lancaster, Pennsylvania, the rate of major depressive disorder is both low (i.e., comparable to that of bipolar disorder)[9] and equivalent for men and women (Egeland et al., 1983). Something about the environment thus appears to interact with a woman's biology to cause a disproportionate incidence of depressive episodes among women (Blumenthal, 1994a).

Research conducted in working-class neighborhoods suggests that the combination of life stress and inadequate social support contributes to women's greater susceptibility to depressive symptoms (Brown et al., 1994). Because women tend to use more ruminative ways of coping (e.g., thinking and talking about a problem, rather than seeking out a distracting activity) and, on average, have less economic power, they may be more likely to perceive their problems as less solvable. That perception increases the likelihood of feeling helpless or entrapped by one's problem. Subtle sex-related differences in hemispheric processing of emotional material may further predispose women to experience emotional stressors more intensely (Baxter et al., 1987). Women are also more likely than men to have experienced past sexual abuse; as noted earlier in this chapter, physical and sexual abuse is strongly associated with the subsequent development of major depressive disorder. Women's greater vulnerability to depression may be amplified by endocrine and reproductive cycling, as well as by a greater susceptibility to hypothyroidism (Thase & Howland, 1995). Menopause, on the other hand, has little bearing on gender differences in depression. Contrary to popular beliefs, menopause does not appear to be associated with increased rates of depression in women (Pearlstein et al., 1997). Untreated mental health problems are likely to worsen at menopause, but menopause by itself is not a risk factor for depression (Pearce et al., 1995; Thacker, 1997). The increased risk for depression prenatally or after childbirth suggests a role for hormonal influences, although evidence also exists for the role of stressful life events. In short, psychosocial and environmental factors likely interact with biological factors to account for greater susceptibility to depression among women.

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[9] A small, albeit noteworthy, sex-related difference is seen in the higher incidence of rapid-cycling bipolar disorder in women (cited in Blumenthal, 1994)

Poor young women (white, black, and Hispanic) appear to be at the greatest risk for depression compared with all other population groups (Miranda & Green, 1999). They have disproportionately higher rates of past exposure to trauma, including rape, sexual abuse, crime victimization, and physical abuse; poorer support systems; and greater barriers to treatment, including financial hardship and lack of insurance (Miranda & Green, 1999). Many of the same problems apply to single mothers, whose risk of depression is double that of married mothers (Brown & Moran, 1997).

The *interaction* between stressful life events, individual experiences, and genetic factors also plays a role in the etiology of depression in women. Some research suggests that genetic factors, which are discussed below, may alter women's sensitivity to the depression-inducing effect of stressful life events (Kendler et al., 1995). A recent report of depression in a sample of 2,662 twins found genetic factors in depression to be stronger for women than men, for whom depression was only weakly familial. For both genders, individual environmental experiences played a large role in depression (Bierut et al., 1999).

Genetic Factors in Depression and Bipolar Disorder

Depression, and especially bipolar disorder, clearly tend to "run in families," and a definite association has been scientifically established (Tsuang & Faraone, 1990). Numerous investigators have documented that susceptibility to a depressive disorder is twofold to fourfold greater among the first-degree relatives of patients with mood disorder than among other people (Tsuang & Faraone, 1990). The risk among first-degree relatives of people with bipolar disorder is about six to eight times greater. Some evidence indicates that first-degree relatives of people with mood disorders are also more susceptible than other people to anxiety and substance abuse disorders (Tsuang & Faraone, 1990).

Remarkable as those statistics may be, they do not by themselves prove a genetic connection. Inasmuch as first-degree relatives typically live in the same environment, share similar values and beliefs, and are subject to similar stressors, the vulnerability to depression could be due to nurture rather than nature. One method to distinguish environmental from genetic factors is to compare concordance rates among same-sex twins. At least in terms of simple genetic theory, a solely hereditary trait that appears in one member of a set of identical (monozygotic) twins also should always appear in the other twin, whereas the trait should appear only 50 percent of the time in same-sex fraternal (dizygotic) twins.

The results of studies comparing the prevalence of depression among twins vary, depending on the specific mood disorder, the age of the study population, and the way the depression is defined. In all instances, however, the reported concordance for mood disorders is greater among monozygotic than among dizygotic twins, and often the proportion is 2 to 1 (Tsuang & Faraone, 1990). In Denmark, Bertelsen and colleagues (1977) found that among 69 monozygotic twins with bipolar illness, 46 co-twins also had bipolar disorder and 14 other co-twins had psychoses, affective personality disorders, or had died by suicide. In studies of monozygotic twins reared separately ("adopted away"), the results also revealed an increased risk of depression and bipolar disorder compared with controls (Mendlewicz & Rainer 1977; Wender et al., 1986). Within the major depressive disorder grouping, greater heritable risk has been associated with more severe, recurrent, or psychotic forms of mood disorders

(Tsuang & Faraone, 1990). Those at greater heritable risk also appear more vulnerable to stressful life events (Kendler et al., 1995).

The availability of modern molecular genetic methods now allows the translation of clinical associations into identification of specific genes (McInnis, 1993; Baron, 1997). Evidence collected to date strongly suggests that vulnerability to mood disorders may be associated with several genes distributed among various chromosomes. For bipolar disorder, numerous distinct chromosomal regions (called loci) show promise, yet the complex nature of inheritance and methodological problems have encumbered investigators (Baron, 1997). Heritability in some cases may be sex linked or vary depending on whether the affected parent is the father or mother of the individual being studied. The genetic process of anticipation (which has been associated with an expansion of trinucleotide repeats) may further alter the expression of illness across generations (McInnis, 1993). Thus, the genetic complexities of the common depressive disorders ultimately may rival their clinical heterogeneity (Tsuang & Faraone, 1990).

Based on a comprehensive review of the genetics literature, the National Institute of Mental Health Genetics Workgroup recently evaluated several mood disorders according to their readiness for large-scale genetics research initiatives. Bipolar disorder was rated in the highest category, meaning that the evidence was strong enough to justify large-scale molecular genetic studies. Depression, eating disorders, obsessive-compulsive disorder, and panic disorder were rated in the second highest category, which called for nonmolecular genetic and/or epidemiological studies to document further their estimated heritability (NIMH, 1998).

Treatment of Mood Disorders

So much is known about the assortment of pharmacological and psychosocial treatments for mood disorders that the most salient problem is not with treatment, but rather with getting people *into* treatment.

Surveys consistently document that a majority of individuals with depression receive no specific form of treatment (Katon et al., 1992; Narrow et al., 1993; Wells et al., 1994; Thase, 1996). Nearly 40 percent of people with bipolar disorder are untreated in 1 year, according to the Epidemiologic Catchment Area survey (Regier et al., 1993). Undertreatment of mood disorders stems from many factors, including societal stigma, financial barriers to treatment, underrecognition by health care providers, and underappreciation by consumers of the potential benefits of treatment (e.g., Regier et al., 1988; Wells et al., 1994; Hirschfeld et al., 1997). The symptoms of depression, such as feelings of worthlessness, excessive guilt, and lack of motivation, also deter consumers from seeking treatment; and members of racial and ethnic minority groups often encounter special barriers, as discussed in Chapter 2.

Mood disorders have profoundly deleterious consequences on well-being: their toll on quality of life and economic productivity matches that of heart disease and is greater than that of peptic ulcer, arthritis, hypertension, or diabetes (Wells et al., 1989).

Stages of Therapy

The treatment of mood disorders is complex because it involves several stages: acute, continuation, and maintenance stages. The stages apply to pharmacotherapy and psychosocial therapy alike. Most patients pass through these stages to restore full functioning.

Acute Phase Therapy

Acute phase treatment with either psychotherapy or pharmacotherapy covers the time period leading up to an initial treatment response. A treatment response is defined by a significant reduction (i.e., $\geq$ 50 percent) in symptom severity, such that the patient no longer meets syndromal criteria for the disorder (Frank et al., 1991b). The acute phase for medication typically requires 6 to 8 weeks (Depression Guideline Panel, 1993), during which patients are seen weekly or biweekly for monitoring of symptoms, side effects, dosage adjustments, and support (Fawcett et al., 1987). Psychotherapies during the acute phase for depression typically consist of 6 to 20 weekly visits.

Outpatient Treatment. In outpatient clinical trials, about 50 to 70 percent of depressed patients who complete treatment respond to either antidepressants or psychotherapies (Depression Guideline Panel, 1993). An acute treatment response includes the effects of placebo expectancy, spontaneous remission, and active treatment. The magnitude of the active treatment effect may be estimated from randomized clinical trials by subtracting the placebo response rate from that of active medication. Overall, the active treatment effect for major depression typically ranges from 20 to 40 percent, after accounting for a placebo response rate of about 30 percent (Depression Guideline Panel, 1993). Although psychotherapy trials do not employ placebos in the form of an inert pill, they do rely on comparisons of active treatment with psychological placebos (e.g., a form of therapy inappropriate for a given disorder), a comparison form of treatment, or wait list (i.e., no therapy). The figures cited above must be understood as rough averages. The efficacy of specific pharmacotherapies and psychotherapies is covered later in this section.

Acute phase therapy is often compromised by patients leaving treatment. Attrition rates from clinical trials often are as high as 30 to 40 percent, and rates of nonadherence[10] are even higher (Depression Guideline Panel, 1993). Medication side effects are a factor, as are other factors such as inadequate psychoeducation (resulting in unrealistic expectations about treatment), ambivalence about seeing a therapist or taking medication, and practical roadblocks (e.g., the cost or accessibility of services).

Another problem is clinician failure to monitor symptomatic response and to change treatments in a timely manner. Antidepressants should be changed if there is no clear effect within 4 to 6 weeks (Nierenberg et al., 1995; Quitkin et al., 1996). Similar data are not available for psychotherapies, but revisions to the treatment plan should be considered, including the addition of antidepressant medication, if there is no symptomatic improvement within 3 or 4 months (Depression Guideline Panel, 1993).

Acute Inpatient Treatment. Hospitalization for acute treatment of depression is necessary for about 5 to 10 percent of major depressive episodes and for up to 50 percent of manic episodes. The principal reasons for hospitalization are overwhelming severity of symptoms and functional incapacity and suicidal or other life-threatening behavior. Hospital median lengths of stay now are about 5 to 7 days for depression and 9 to 14 days for mania. Such abbreviated stays have reduced costs but necessitate greater transitional or aftercare services. Few severely depressed or manic people are in remission after only 1 to 2 weeks of treatment.

Electroconvulsive Therapy. As described above, first-line treatment for most people with depression today consists of antidepressant medication, psychotherapy, or the combination (Potter et al., 1991; Depression Guideline Panel, 1993). In situations where these options are not effective or too slow (for example, in a person with delusional depression and intense, unremitting suicidality) electroconvulsive therapy (ECT) may be considered. ECT, sometimes referred to as *electroshock* or *shock treatment,* was developed in the 1930s based on the mistaken belief that epilepsy (seizure disorder) and schizophrenia could not exist at the same time in an individual. Accumulated clinical experience—later confirmed in controlled clinical trials, which included the use of simulated or "sham" ECT as a control (Janicak et al., 1985)—determined ECT to be highly effective against severe depression, some acute psychotic states, and mania (Small et al., 1988). No controlled study has shown any other treatment to have superior efficacy to ECT in the treatment of depression (Janicak et al., 1985; Rudorfer et al., 1997). ECT has not been demonstrated to be effective in dysthymia, substance abuse, or anxiety or personality disorders. The foregoing conclusions, and many of those discussed below, are the products of review of extensive research conducted over several decades (Depression Guideline Panel, 1993; Rudorfer et al., 1997) as well as by an independent panel of scientists, practitioners, and consumers (NIH & NIMH Consensus Conference, 1985).

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[10] Nonadherence is defined as lack of adherence to prescribed activities such as keeping appointments, taking medication, and completing assignments.

ECT consists of a series of brief generalized seizures induced by passing an electric current through the brain by means of two electrodes placed on the scalp. A typical course of ECT entails 6 to 12 treatments, administered at a rate of three times per week, on either an inpatient or outpatient basis. The exact mechanisms by which ECT exerts its therapeutic effect are not yet known. The production of an adequate, generalized seizure using the proper amount of electrical stimulation at each treatment session is required for therapeutic efficacy (Sackheim et al., 1993).

With the development of effective medications for the treatment of major mental disorders a half-century ago, the need for ECT lessened but did not disappear. Prior to that time, ECT often had been administered for a variety of conditions for which it is not effective, and administered without anesthesia or neuromuscular blockade. The result was grand mal seizures that could produce injuries and even fractures. Despite the availability of a range of effective antidepressant medications and psychotherapies, as discussed above, ECT continues to be used (Rosenbach et al., 1997), occupying a narrower but important niche. It is generally reserved for the special circumstances where the usual first-line treatments are ineffective or cannot be taken, or where ECT is known to be particularly beneficial, such as depression or mania accompanied by psychosis or catatonia (NIH & NIMH Consensus Conference, 1985; Depression Guideline Panel, 1993; Potter & Rudorfer, 1993). Examples of specific indications include depression unresponsive to multiple medication trials, or accompanied by a physical illness or pregnancy, which renders the use of a usually preferred antidepressant dangerous to the patient or to a developing fetus. Under such circumstances, carefully weighing risks and benefits, ECT may be the safest treatment option for severe depression. It should be administered under controlled conditions, with appropriate personnel (Rudorfer et al., 1997).

Although the average 60 to 70 percent response rate seen with ECT is comparable to that obtained with pharmacotherapy, there is evidence that the antidepressant effect of ECT occurs faster than that seen with medication, encouraging the use of ECT where depression is accompanied by potentially uncontrollable suicidal ideas and actions (Rudorfer et al., 1997). However, ECT does not exert a long-term protection against suicide. Indeed, it is now recognized that a single course of ECT should be regarded as a short-term treatment for an acute episode of illness. To sustain the response to ECT, continuation treatment, often in the form of antidepressant and/or mood stabilizer medication, must be instituted (Sackeim, 1994). Individuals who repeatedly relapse following ECT despite continuation medication may be candidates for maintenance ECT, delivered on an outpatient basis at a rate of one treatment weekly to as infrequently as monthly (Sackeim, 1994; Rudorfer et al., 1997).

The major risks of ECT are those of brief general anesthesia, which was introduced along with muscle relaxation and oxygenation to protect against injury and to reduce patient anxiety. There are virtually no absolute health contraindications precluding its use where warranted (Potter & Rudorfer, 1993; Rudorfer et al., 1997).

The most common adverse effects of this treatment are confusion and memory loss for events surrounding the period of ECT treatment. The confusion and disorientation seen upon awakening after ECT typically clear within an hour. More persistent memory problems are variable. Most typical with standard, bilateral electrode placement (one electrode on each side of the head) has been a pattern of loss of memories for the time of the ECT series and extending back an average of 6 months, combined with impairment with learning new information, which continues for perhaps 2 months following ECT (NIH & NIMH Consensus Conference, 1985). Well-designed neuropsychological studies have consistently shown that by several months after completion of ECT, the ability to learn and remember are normal (Calev, 1994). Although most patients return to full functioning following successful ECT, the degree of post-treatment memory impairment and resulting impact on functioning are highly variable across individuals (NIH & NIMH Consensus Conference, 1985; CMHS, 1998). While clearly the exception rather than the rule, no reliable data on the incidence of severe post-ECT memory impairment are available. Fears that ECT causes gross structural brain pathology have not been supported by decades of methodologically sound research in both humans and animals (NIH & NIMH Consensus Conference, 1985; Devanand et al., 1994; Weiner & Krystal, 1994; Greenberg, 1997; CMHS, 1998). The decision to use ECT must be evaluated for each individual, weighing the potential benefits and known risks of all available and appropriate treatments in the context of informed consent (NIH & NIMH Consensus Conference, 1985).

Advances in treatment technique over the past generation have enabled a reduction of adverse cognitive effects of ECT (NIH & NIMH Consensus Conference, 1985; Rudorfer et al., 1997). Nearly all ECT devices deliver a lower current, *brief-pulse* electrical stimulation, rather than the original sine wave output; with a brief pulse electrical wave, a therapeutic seizure may be induced with as little as one-third the electrical power as with the older method, thereby reducing the potential for confusion and memory disturbance (Andrade et al., 1998). Placement of both stimulus electrodes on one side of the head ("unilateral" ECT), over the nondominant (generally right) cerebral hemisphere, results in delivery of the initial electrical stimulation away from the primary learning and memory centers. According to several controlled trials, unilateral ECT is associated with virtually no detectable, persistent memory loss (Horne et al., 1985; NIH Consensus Conference, 1985; Rudorfer et al., 1997). However, most clinicians find unilateral ECT less potent and more slowly acting an intervention than conventional bilateral ECT, particularly in the most severe cases of depression or in mania. One approach that is sometimes used is to begin a trial of ECT with unilateral electrode placement and switch to bilateral treatment after about six treatments if there has been no response. Research has demonstrated that the relationship of electrical dose to clinical response differs depending on electrode placement: for bilateral ECT, as long as an adequate seizure is obtained, any additional dosage will merely add to the cognitive toxicity, whereas for unilateral electrode placement, a therapeutic effect will not be achieved unless the electrical stimulus is more than minimally above the seizure threshold (Sackeim et al., 1993). Even a moderately high electrical dosage in unilateral ECT still has fewer cognitive adverse effects than bilateral ECT. On the other hand, high-dose bilateral ECT may be unnecessarily risky and may be a preventable cause of severe memory impairment. Some types of medication, such as lithium, also add to confusion and cognitive impairment when given during a course of ECT and are best avoided. Medications that raise the seizure threshold and make it harder to obtain a therapeutic effect from ECT, including anticonvulsants and some minor tranquilizers, may also need to be tapered or discontinued.

Informed consent is an integral part of the ECT process (NIH & NIMH Consensus Conference, 1985). The potential benefits and risks of this treatment, and of available alternative interventions, should be carefully reviewed and discussed with patients and, where appropriate, family or friends. Prospective candidates for ECT should be informed, for example, that its benefits are short-lived without active continuation treatment, and that there may be some risk of permanent severe memory loss after ECT. In most cases of depression, the benefit-to-risk ratio will favor the use of medication and/or psychotherapy as the preferred course of action (Depression Guideline Panel, 1993). Where medication has not succeeded, or is fraught with unusual risk, or where the potential benefits of ECT are great, such as in delusional depression, the balance of potential benefits to risks may tilt in favor of ECT. Active discussion with the treatment team, supplemented by the growing amount of printed and videotaped information packages for consumers, is necessary in the decisionmaking process, both prior to and throughout a course of ECT. Consent may be revoked at any time during a series of ECT sessions.

Although many people have fears related to stories of forced ECT in the past, the use of this modality on an involuntary basis today is uncommon. Involuntary

ECT may not be initiated by a physician or family member without a judicial proceeding. In every state, the administration of ECT on an involuntary basis requires such a judicial proceeding at which patients may be represented by legal counsel. As a rule, such petitions are granted only where the prompt institution of ECT is regarded as potentially lifesaving, as in the case of a person who is in grave danger because of lack of food or fluid intake caused by catatonia. Recent epidemiological surveys show that the modern use of ECT is generally limited to evidence-based indications (Hermann et al., 1999). Indeed, concern has been raised that in some settings, particularly in the public sector and outside major metropolitan areas, ECT may be underutilized due to the wide variability in the availability of this treatment across the country (Hermann et al., 1995). Consequently, minority patients tend to be underrepresented among those receiving ECT (Rudorfer et al., 1997).

On balance, the evidence supports the conclusion that modern ECT is among those treatments effective for the treatment of select severe mental disorders, when used in accord with current standards of care, including appropriate informed consent.

Continuation Phase Therapy

Successful acute phase antidepressant pharmacotherapy or ECT should almost always be followed by at least 6 months of continued treatment (Prien & Kupfer, 1986; Depression Guideline Panel, 1993; Rudorfer et al., 1997). During this phase, known as the continuation phase, most patients are seen biweekly or monthly. The primary goal of continuation pharmacotherapy is to prevent relapse (i.e., an exacerbation of symptoms sufficient to meet syndromal criteria). Continuation pharmacotherapy reduces the risk of relapse from 40-60 percent to 10-20 percent (Prien & Kupfer, 1986; Thase, 1993). Relapse despite continuation pharmacotherapy might suggest either nonadherence (Myers & Branthwaithe, 1992) or loss of a placebo response (Quitkin et al., 1993a).

A second goal of continuation pharmacotherapy is consolidation of a response into a complete remission and subsequent recovery (i.e., 6 months of sustained remission). A remission is defined as a complete resolution of affective symptoms to a level similar to healthy people (Frank et al., 1991a). As residual symptoms are associated with increased relapse risk (Keller et al., 1992; Thase et al., 1992), recovery should be achieved before withdrawing antidepressant pharmacotherapy.

Many psychotherapists similarly taper a successful course of treatment by scheduling several sessions (every other week or monthly) prior to termination. There is some evidence, albeit weak, that relapse is less common following successful treatment with one type of psychotherapy—cognitive-behavioral therapy—than with antidepressants (Kovacs et al., 1981; Blackburn et al., 1986; Simons et al., 1986; Evans et al., 1992). If confirmed, this advantage may offset the greater short-term costs of psychotherapy.

Maintenance Phase Therapies

Maintenance pharmacotherapy is intended to prevent future recurrences of mood disorders (Kupfer, 1991; Thase, 1993; Prien & Kocsis, 1995). A recurrence is viewed as a new episode of illness, in contrast to relapse, which represents reactivation of the index episode (Frank et al., 1991a). Maintenance pharmacotherapy is typically recommended for individuals with a history of three or more depressive episodes, chronic depression, or bipolar disorder (Kupfer, 1991; Thase, 1993; Prien & Kocsis, 1995). Maintenance pharmacotherapy, which may extend for years, typically requires monthly or quarterly visits.

Longer term, preventive psychotherapy to prevent recurrences has not been studied extensively. However, in one study of patients with highly recurrent depression, monthly sessions of interpersonal psychotherapy were significantly more effective than placebo but less effective than pharmacotherapy (Frank et al., 1991a).

Specific Treatments for Episodes of Depression and Mania

This section describes specific types of pharmacotherapies and psychosocial therapies for *episodes* of depression and mania. Treatment generally targets symptom patterns rather than specific disorders. Differences in the treatment strategy for unipolar and bipolar depression are described where relevant.

Treatment of Major Depressive Episodes

Pharmacotherapies

Antidepressant medications are effective across the full range of severity of major depressive episodes in major depressive disorder and bipolar disorder (American Psychiatric Association, 1993; Depression Guideline Panel, 1993; Frank et al., 1993). The degree of effectiveness, however, varies according to the intensity of the depressive episode. With mild depressive episodes, the overall response rate is about 70 percent, including a placebo rate of about 60 percent (Thase & Howland, 1995). With severe depressive episodes, the overall response rate is much lower, as is the placebo rate. For example, with psychotic depression, the overall response rate to any one drug is only about 20 to 40 percent (Spiker, 1985), including a placebo response rate of less than 10 percent (Spiker & Kupfer, 1988; Schatzberg & Rothschild, 1992). Psychotic depression is treated with either an antidepressant/antipsychotic combination *or* ECT (Spiker, 1985; Schatzberg & Rothschild, 1992).

There are four major classes of antidepressant medications. The tricyclic and heterocyclic antidepressants (TCAs and HCAs) are named for their chemical structure. The MAOIs and SSRIs are classified by their initial neurochemical effects. In general, MAOIs and SSRIs increase the level of a target neurotransmitter by two distinct mechanisms. But, as discussed below, these classes of medications have many other effects. They also have some differential effects depending on the race or ethnicity of the patient.

The mode of action of antidepressants is complex and only partly understood. Put simply, most antidepressants are designed to heighten the level of a target neurotransmitter at the neuronal synapse. This can be accomplished by one or more of the following therapeutic actions: boosting the neurotransmitter's synthesis, blocking its degradation, preventing its reuptake from the synapse into the presynaptic neuron, or mimicking its binding to postsynaptic receptors. To make matters more complicated, many antidepressant drugs affect more than one neurotransmitter. Explaining how any one drug alleviates depression probably entails multiple therapeutic actions, direct and indirect, on more than one neurotransmitter system (Feighner, 1999).

Selection of a particular antidepressant for a particular patient depends upon the patient's past treatment history, the likelihood of side effects, safety in overdose, and expense (Depression Guideline Panel, 1993). A vast majority of U.S. psychiatrists favor the SSRIs as "first-line" medications (Olfson & Klerman, 1993). These agents are viewed more favorably than the TCAs because of their ease of use, more manageable side effects, and safety in overdose (Kapur et al., 1992; Preskorn & Burke, 1992). Perhaps the major drawback of the SSRIs is their expense: they are only available as name brands (until 2002 when they begin to come off patent). At minimum, SSRI therapy costs about $80 per month (Burke et al., 1994), and patients taking higher doses face proportionally greater costs.

Four SSRIs have been approved by the FDA for treatment of depression: fluoxetine, sertraline, paroxetine, and citalopram. A fifth SSRI, fluvoxamine, is approved for treatment of obsessive-compulsive disorder, yet is used off-label for depression.[11] There are few compelling reasons to pick one SSRI over another for treatment of uncomplicated major depression, because they are more similar than different (Aguglia et al., 1993; Schone & Ludwig, 1993; Tignol, 1993; Preskorn, 1995). There are, however, several distinguishing pharmacokinetic differences between SSRIs, including elimination half-life (the time it takes for the plasma level of the drug to decrease 50 percent from steady-state), propensity for drug-drug interactions (e.g., via inhibition of hepatic enzymes), and antidepressant activity of metabolite(s) (DeVane, 1992). In general, SSRIs are more likely to be metabolized more slowly by African Americans and Asians, resulting in higher blood levels (Lin et al., 1997).

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[11] Technically, FDA approves drugs for a selected indication (a disorder in a certain population). However, once the drug is marketed, doctors are at liberty to prescribe it for unapproved (off-label) indications.

The SSRIs as a class of drugs have their own class-specific side effects, including nausea, diarrhea, headache, tremor, daytime sedation, failure to achieve orgasm, nervousness, and insomnia. Attrition from acute phase therapy because of side effects is typically 10 to 20 percent (Preskorn & Burke, 1992). The incidence of treatment-related suicidal thoughts for the SSRIs is low and comparable to the rate observed for other antidepressants (Beasley et al., 1991; Fava & Rosenbaum, 1991), despite reports to the contrary (Breggin & Breggin, 1994).

Some concern persists that the SSRIs are less effective than the TCAs for treatment of severe depressions, including melancholic and psychotic subtypes (Potter et al., 1991; Nelson, 1994). Yet there is no definitive answer (Danish University Antidepressant Group, 1986, 1990; Pande & Sayler, 1993; Roose et al., 1994; Stuppaeck et al., 1994).

Side effects and potential lethality in overdose are the major drawbacks of the TCAs. An overdose of as little as 7-day supply of a TCA can result in potentially fatal cardiac arrhythmias (Kapur et al., 1992). TCA treatment is typically initiated at lower dosages and titrated upward with careful attention to response and side effects. Doses for African Americans and Asians should be monitored more closely, because their slower metabolism of TCAs can lead to higher blood concentrations (Lin et al., 1997). Similarly, studies also suggest that there may be gender differences in drug metabolism and that plasma levels may change over the course of the menstrual cycle (Blumenthal, 1994b).

In addition to the four major classes of antidepressants are bupropion, which is discussed below, and three newer FDA-approved antidepressants that have mixed or compound synaptic effects. Venlafaxine, the first of these newer antidepressants, inhibits reuptake of both serotonin and, at higher doses, norepinephrine. In contrast to the TCAs, venlafaxine has somewhat milder side effects (Bolden-Watson & Richelson, 1993), which are like those of the SSRIs. Venlafaxine also has a low risk of cardiotoxicity and, although experience is limited, it appears to be less toxic than the others in overdose. Venlafaxine has shown promise in treatment of severe (Guelfi et al., 1995) or refractory (Nierenberg et al., 1994) depressive states and is superior to fluoxetine in one inpatient study (Clerc et al., 1994). Venlafaxine also occasionally causes increased blood pressure, and this can be a particular concern at higher doses (Thase, 1998).

Nefazodone, the second newer antidepressant, is unique in terms of both structure and neurochemical effects (Taylor et al., 1995). In contrast to the SSRIs, nefazodone improves sleep efficiency (Armitage et al., 1994). Its side effect profile is comparable to the other newer antidepressants, but it has the advantage of a lower rate of sexual side effects (Preskorn, 1995). The more recently FDA-approved antidepressant, mirtazapine, blocks two types of serotonin receptors, the 5-HT_2 and 5-HT_3 receptors (Feighner, 1999). Mirtazapine is also a potent antihistamine and tends to be more sedating than most other newer antidepressants. Weight gain can be another troublesome side effect.

Figure 4-2 presents summary findings on newer pharmacotherapies from a recent review of the treatment of depression by the Agency for Health Care Policy and Research (AHCPR, 1999). There have been few studies of gender differences in clinical response to treatments for depression. A recent report (Kornstein et al., in press) found women with chronic depression to respond better to a SSRI than a tricyclic, yet the opposite for men. This effect was primarily in premenopausal women. The AHCPR report (1999) also noted that there were almost no data to address the efficacy of pharmacotherapies in post partum or pregnant women.

Alternate Pharmacotherapies

Regardless of the initial choice of pharmacotherapy, about 30 to 50 percent of patients do not respond to the initial medication. It has not been established firmly whether patients who respond poorly to one class of antidepressants should be switched automatically to an alternate class (Thase & Rush, 1997). Several studies have examined the efficacy of the TCAs and SSRIs when used in sequence (Peselow et al., 1989; Beasley et al., 1990). Approximately 30 to 50 percent of those not responsive to one class will respond to the other (Thase & Rush, 1997).

Among other types of antidepressants, the MAOIs and bupropion are important alternatives for SSRI and TCA nonresponders (Thase & Rush, 1995). These agents also may be relatively more effective than TCAs or SSRIs for treatment of depressions characterized by atypical or reversed vegetative symptoms (Goodnick & Extein, 1989; Quitkin et al., 1993b; Thase et al., 1995). Bupropion and the MAOIs also are good choices to treat bipolar depression (Himmelhoch et al., 1991; Thase et al., 1992; Sachs et al., 1994). Bupropion also has the advantage of a low rate of sexual side effects (Gardner & Johnston, 1985; Walker et al., 1993).

Bupropion's efficacy and overall side effect profile might justify its first-line use for all types of depression (e.g., Kiev et al., 1994). Furthermore, bupropion has a novel neurochemical profile in terms of effects on dopamine and norepinephrine (Ascher et al., 1995). However, worries about an increased risk of seizures delayed bupropion's introduction to the U.S. market by more than 5 years (Davidson, 1989). Although clearly effective for a broad range of depressions, use of the MAOIs has been limited for decades by concerns that when taken with certain foods containing the chemical tyramine (for example, some aged cheeses and red wines); these medications may cause a potentially lethal hypertensive reaction (Thase et al., 1995). There has been continued interest in development of safer, selective and reversible MAOIs.

Hypericum (St. John's Wort). The widespread publicity and use of the botanical product from the yellow-flowering *Hypericum perforatum* plant with or without medical supervision is well ahead of the science database supporting the effectiveness of this putative antidepressant. Controlled trials, mainly in Germany, have been positive in mild-to-moderate depression, with only mild gastrointestinal side effects reported (Linde et al., 1996). However, most of those studies were methodologically flawed, in areas including diagnosis (more similar to adjustment disorder with depressed mood than major depression), length of trial (often an inadequate 4 weeks), and either lack of placebo control or unusually low or high placebo response rates (Salzman, 1998).

Figure 4-2. Treatment of depression—newer pharmacotherapies: Summary findings

- Newer antidepressant drugs* are effective treatments for major depression and dysthymia.
  - They are efficacious in primary care and specialty mental health care settings:
    - Major depression:
      50 percent response to active agent
      32 percent response to placebo
    - Dysthymia (fluoxetine, sertraline, and amisulpride):
      59 percent response to active agent
      37 percent response to placebo
- Both older and newer antidepressants demonstrate similar efficacy.
- Drop-out rates due to all causes combined are similar for newer and older agents:
  - Drop-out rates due to adverse effects are slightly higher for older agents.
  - Newer agents are often easier to use because of single daily dosing and less titration.

*SSRIs and all other antidepressants marketed subsequently.
Source: AHCPR, 1999.

Post-marketing surveillance in Germany, which found few adverse effects of *Hypericum*, depended upon spontaneous reporting of side effects by patients, an approach that would not be considered acceptable in this country (Deltito & Beyer, 1998). In clinical use, the most commonly encountered adverse effect noted appears to be sensitivity to sunlight.

Basic questions about mechanism of action and even the optimal formulation of a pharmaceutical product from the plant remain; dosage in the randomized German trials varied by sixfold (Linde et al., 1996). Several pharmacologically active components of St. John's wort, including hypericin, have been identified (Nathan, 1999); although their long half-lives in theory should permit once daily dosing, in practice a schedule of 300 mg three times a time is most commonly used. While initial speculation about significant MAO-inhibiting properties of hypericum have been largely discounted, possible serotonergic mechanisms suggest that combining this agent with an SSRI or other serotonergic antidepressant should be approached with caution. However, data regarding safety of hypericum in preclinical models or clinical samples are few (Nathan, 1999). At least two placebo-controlled trials in the United States are under way to compare the efficacy of *Hypericum* with that of an SSRI.

Augmentation Strategies

The transition from one antidepressant to another is time consuming, and patients sometimes feel worse in the process (Thase & Rush, 1997). Many clinicians bypass these problems by using a second medication to augment an ineffective antidepressant. The best studied strategies of this type are lithium augmentation, thyroid augmentation, and TCA-SSRI combinations (Nierenberg & White, 1990; Thase & Rush, 1997; Crismon et al., 1999).

Increasingly, clinicians are adding a noradrenergic TCA to an ineffective SSRI or vice versa. In an earlier era, such polypharmacy (the prescription of multiple drugs at the same time) was frowned upon. Thus far, the evidence supporting TCA-SSRI combinations is not conclusive (Thase & Rush, 1995). Caution is needed when using these agents in combination because SSRIs inhibit metabolism of several TCAs, resulting in a substantial increase in blood levels and toxicity or other adverse side effects from TCAs (Preskorn & Burke, 1992).

Psychotherapy and Counseling

Many people prefer psychotherapy or counseling over medication for treatment of depression (Roper, 1986; Seligman,1995). Research conducted in the past two decades has helped to establish at least several newer forms of time-limited psychotherapy as being as effective as antidepressant pharmacotherapy in mild-to-moderate depressions (DiMascio et al., 1979; Elkin et al., 1989; Hollon et al., 1992; Depression Guideline Panel, 1993; Thase, 1995; Persons et al., 1996). The newer depression-specific therapies include cognitive-behavioral therapy (Beck et al., 1979) and interpersonal psychotherapy (Klerman et al., 1984). These approaches use a time-limited approach, a present tense ("here-and-now") focus, and emphasize patient education and active collaboration. Interpersonal psychotherapy centers around four common problem areas: role disputes, role transitions, unresolved grief, and social deficits. Cognitive-behavioral therapy takes a more structured approach by emphasizing the interactive nature of thoughts, emotions, and behavior. It also helps the depressed patient to learn how to improve coping and lessen symptom distress.

There is no evidence that cognitive-behavioral therapy and interpersonal psychotherapy are differentially effective (Elkin et al., 1989; Thase, 1995). As reported earlier, both therapies appear to have some relapse prevention effects, although they are much less studied than the pharmacotherapies. Other more traditional forms of counseling and psychotherapy have not been extensively studied using a randomized clinical trial design (Depression Guideline Panel, 1993). It is important to determine if these more traditional treatments, as commonly practiced, are as effective as interpersonal psychotherapy or cognitive-behavioral therapy.

The brevity of this section reflects the succinctness of the findings on the effectiveness of these interventions as well as the lack of differential responses and "side effects." It does not reflect a preference or superiority of medication except in conditions such as psychotic depression where psychotherapies are not effective.

Bipolar Depression

Treatment of bipolar depression[12] has received surprisingly little study (Zornberg & Pope, 1993). Most psychiatrists prescribe the same antidepressants for treatment of bipolar depression as for major depressive disorder, although evidence is lacking to support this practice. It also is not certain that the same strategies should be used for treatment of depression in bipolar II (i.e., major depression plus a history of hypomania) and bipolar I (i.e., major depression with a history of at least one prior manic episode) (DSM-IV).

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[12] Bipolar depression refers to episodes with symptoms of depression in patients diagnosed with bipolar disorder.

Pharmacotherapy of bipolar depression typically begins with lithium or an alternate mood stabilizer (DSM-IV; Frances et al., 1996). Mood stabilizers reduce the risk of cycling and have modest antidepressant effects; response rates of 30 to 50 percent are typical (DSM-IV; Zornberg & Pope, 1993). For bipolar depressions refractory to mood stabilizers, an antidepressant is typically added. Bipolar depression may be more responsive to nonsedating antidepressants, including the MAOIs, SSRIs, and bupropion (Cohn et al., 1989; Haykal & Akiskal, 1990; Himmelhoch et al., 1991; Peet, 1994; Sachs et al., 1994).The optimal length of continuation phase pharmacotherapy of bipolar depression has not been established empirically (DSM-IV). During the continuation phase, the risk of depressive relapse must be counterbalanced against the risk of inducing mania or rapid cycling (Kukopulos et al., 1980; Wehr & Goodwin, 1987; Solomon et al., 1995). Although not all studies are in agreement, antidepressants may increase mood cycling in a vulnerable subgroup, such as women with bipolar II disorder (Coryell et al., 1992; Bauer et al., 1994). Lithium is associated with increased risk of congenital anomalies when taken during the first trimester of pregnancy, and the anticonvulsants are contraindicated (see Cohen et al., 1994, for a review). This is problematic in view of the high risk of recurrence in pregnant bipolar women (Viguera & Cohen 1998).

Pharmacotherapy, Psychosocial Therapy, and Multimodal Therapy

The relative efficacy of pharmacotherapy and the newer forms of psychosocial treatment, such as interpersonal psychotherapy and the cognitive-behavioral therapies, is a controversial topic (Meterissian & Bradwejn, 1989; Klein & Ross, 1993; Munoz et al., 1994; Persons et al., 1996). For major depressive episodes of mild to moderate severity, meta-analyses of randomized clinical trials document the relative equivalence of these treatments (Dobson, 1989; Depression Guideline Panel, 1993). Yet for patients with bipolar and psychotic depression, who were excluded from these studies, pharmacotherapy is required: there is no evidence that these types of depressive episodes can be effectively treated with psychotherapy alone (Depression Guideline Panel, 1993; Thase, 1995). Current standards of practice suggest that therapists who withhold somatic treatments (i.e., pharmacotherapy or ECT) from such patients risk malpractice (DSM-IV; Klerman, 1990; American Psychiatric Association, 1993; Depression Guideline Panel, 1993).

For patients hospitalized with depression, somatic therapies also are considered the standard of care (American Psychiatric Association, 1993). Again, there is little evidence for the efficacy of psychosocial treatments alone when used instead of pharmacotherapy, although several studies suggest that carefully selected inpatients may respond to intensive cognitive-behavioral therapy (DeJong et al., 1986; Thase et al., 1991). However, in an era in which inpatient stays are measured in days, rather than in weeks, this option is seldom feasible. Combined therapies emphasizing both pharmacologic and intensive psychosocial treatments hold greater promise to improve the outcome of hospitalized patients, particularly if inpatient care is followed by ambulatory treatment (Miller et al., 1990; Scott, 1992).

Combined therapies—also called multimodal treatments—are especially valuable for outpatients with severe forms of depression. According to a recent meta-analysis of six studies, combined therapy (cognitive or interpersonal psychotherapy *plus* pharmacotherapy) was significantly more effective than psychotherapy alone for more severe recurrent depression. In milder depressions, psychotherapy alone was nearly as effective as combined therapy (Thase et al., 1997b). This meta-analysis was unable to compare combined therapy with pharmacotherapy alone or placebo due to an insufficient number of patients.

In summary, the DSM-IV definition of major depressive disorder spans a heterogenous group of conditions that benefit from psychosocial and/or pharmacological therapies. People with mild to moderate depression respond to psychotherapy or pharmacotherapy alone. People with severe depression require pharmacotherapy or ECT and they may also benefit from the addition of psychosocial therapy.

Preventing Relapse of Major Depressive Episodes

Recurrent Depression. Maintenance pharmacotherapy is the best-studied means to reduce the risk of recurrent depression (Prien & Kocsis, 1995; Thase & Sullivan, 1995). The magnitude of effectiveness in prevention of recurrent depressive episodes depends on the dose of the active agent used, the inherent risk of the population (i.e., chronicity, age, and number of prior episodes), the length of time being considered, and the patient's adherence to the treatment regimen (Thase, 1993). Early studies, which tended to use lower dosages of medications, generally documented a twofold advantage relative to placebo (e.g., 60 vs. 30 percent) (Prien & Kocsis, 1995). In a more recent study of recurrent unipolar depression, the drug-placebo difference was nearly fivefold (Frank et al., 1990; Kupfer et al., 1992). This trial, in contrast to earlier randomized clinical trials, used a much higher dosage of imipramine, suggesting that full-dose maintenance pharmacotherapy may improve prophylaxis. Indeed, this was subsequently confirmed in a randomized clinical trial comparing full- and half-dose maintenance strategies (Frank et al., 1993).

There are few published studies on the prophylactic benefits of long-term pharmacotherapy with SSRIs, bupropion, nefazodone, or venlafaxine. However, available studies uniformly document 1 year efficacy rates of 80 to 90 percent in preventing recurrence of depression (Montgomery et al., 1988; Doogan & Caillard, 1992; Claghorn & Feighner, 1993; Duboff, 1993; Shrivastava et al., 1994; Franchini et al., 1997; Stewart et al., 1998). Thus, maintenance therapy with the newer agents is likely to yield outcomes comparable to the TCAs (Thase & Sullivan, 1995).

How does maintenance pharmacotherapy compare with psychotherapy? In one study of recurrent depression, monthly sessions of maintenance interpersonal psychotherapy had a 3-year success rate of about 35 percent (i.e., a rate falling between those for active and placebo pharmacotherapy) (Frank et al., 1990). Subsequent studies found maintenance interpersonal psychotherapy to be either a powerful or ineffective prophylactic therapy, depending on the patient/treatment match (Kupfer et al., 1990; Frank et al., 1991a; Spanier et al., 1996).

Bipolar Depression. No recent randomized clinical trials have examined prophylaxis against recurrent depression in bipolar disorder. In one older, well-controlled study, recurrence rates of more than 60 percent were observed despite maintenance treatment with lithium, either alone or in combination with imipramine (Shapiro et al., 1989).

Treatment of Mania

Acute Phase Efficacy

Success rates of 80 to 90 percent were once expected with lithium for the acute phase treatment of mania (e.g., Schou, 1989); however, lithium response rates of only 40 to 50 percent are now commonplace (Frances et al., 1996). Most recent studies thus underscore the limitations of lithium in mania (e.g., Gelenberg et al., 1989; Small et al., 1991; Freeman et al., 1992; Bowden et al., 1994). The apparent decline in lithium responsiveness may be partly due to sampling bias (i.e., university hospitals treat more refractory patients), but could also be attributable to factors such as younger age of onset, increased drug abuse comorbidity, or shorter therapeutic trials necessitated by briefer hospital stay (Solomon et al., 1995). The effectiveness of acute phase lithium treatment also is partially dependent on the clinical characteristics of the manic episode: dysphoric/mixed, psychotic, and rapid cycling episodes are less responsive to lithium alone (DSM-IV; Solomon et al., 1995).

A number of other medications initially developed for other indications are increasingly used for lithium-refractory or lithium-intolerant mania. The efficacy of two medications, the anticonvulsants carbamazepine and divalproex sodium, has been documented in randomized clinical trials (e.g., Small et al., 1991; Freeman et al., 1992; Bowden et al., 1994; Keller et al., 1992). Divalproex sodium has received FDA approval for the treatment of mania. The specific mechanisms of action for these agents have not been established, although they may stabilize neuronal membrane systems, including the cyclic adenosine monophosphate second messenger system (Post, 1990). The anticonvulsant medications under investigation for their effectiveness in mania include lamotrigine and gabapentin.

Another newer treatment, verapamil, is a calcium channel blocker initially approved by the FDA for treatment of cardiac arrhythmias and hypertension. Since the mid-1980s, clinical reports and evidence from small randomized clinical trials suggest that the calcium channel blockers may have antimanic effects (Dubovsky et al., 1986; Garza-Trevino et al., 1992; Janicak et al., 1992, 1998). Like lithium and the anticonvulsants, the mechanism of action of verapamil has not been established. There is evidence of abnormalities of intracellular calcium levels in bipolar disorder (Dubovsky et al., 1992), and calcium's role in modulating second messenger systems (Wachtel, 1990) has spurred continued interest in this class of medication. If effective, verapamil does have the additional advantage of having a lower potential for causing birth defects than does lithium, divalproex, or carbamazepine.

Adjunctive neuroleptics and high-potency benzodiazepines are used often in combination with mood stabilizers to treat mania. The very real risk of tardive dyskinesia has led to a shift in favor of adjunctive use of benzodiazepines instead of neuroleptics for acute stabilization of mania (Chouinard, 1988; Lenox et al., 1992). The novel antipsychotic clozapine has shown promise in otherwise refractory manic states (Suppes et al., 1992), although such treatment requires careful monitoring to help protect against development of agranulocytosis, a potentially lethal bone marrow toxicity. Other newer antipsychotic medications, including risperidone and olanzapine, have safer side effect profiles than clozapine and are now being studied in mania. For manic patients who are not responsive to or tolerant of pharmacotherapy, ECT is a viable alternative (Black et al., 1987; Mukherjee et al., 1994). Further discussion of antipsychotic drugs and their side effects is found in the section on schizophrenia

Maintenance Treatment to Prevent Recurrences of Mania

The efficacy of lithium for prevention of mania also appears to be significantly lower now than in previous decades; recurrence rates of 40 to 60 percent are now typical despite ongoing lithium therapy (Prien et al., 1984; Gelenberg et al., 1989; Winokur et al., 1993). Still, more than 20 studies document the effectiveness of lithium in preventing suicide (Goodwin & Jamison, 1990). Medication noncompliance almost certainly plays a role in the failure of longer term lithium maintenance therapy (Aagaard et al., 1988). Indeed, abrupt discontinuation of lithium has been shown to accelerate the risk of relapse (Suppes et al., 1993). Medication "holidays" may similarly induce a lithium-refractory state (Post, 1992), although data are conflicting (Coryell et al., 1998). As noted earlier, antidepressant cotherapy also may accelerate cycle frequency or induce lithium-resistant rapid cycling (Kukopulos et al., 1980; Wehr & Goodwin, 1987).

With increasing recognition of the limitations of lithium prophylaxis, the anticonvulsants are used increasingly for maintenance therapy of bipolar disorder. Several randomized clinical trials have demonstrated the prophylactic efficacy of carbamazepine (Placidi et al., 1986; Lerer et al., 1987; Coxhead et al., 1992), whereas the value of divalproex preventive therapy is only supported by uncontrolled studies (Calabrese & Delucchi, 1990; McElroy et al., 1992; Post, 1990). Because of increased teratogenic risk associated with these agents, there is a need to obtain and evaluate information on alternative interventions for women with bipolar disorder of childbearing age.

Service Delivery for Mood Disorders

The mood disorders are associated with significant suffering and high social costs, as explained above (Broadhead et al., 1990; Greenberg et al., 1993; Wells et al., 1989; Wells et al., 1996). Many treatments are efficacious, yet in the case of depression, significant numbers of individuals either receive no care or inappropriate care (Katon et al., 1992; Narrow et al., 1993; Wells et al., 1994; Thase, 1996). Limitations in insurance benefits or in the management strategies employed in managed care arrangements may make it impossible to deliver recommended treatments. In addition, treatment outcome in real-world practice is not as effective as that demonstrated in clinical trials, a problem known as the gap between efficacy and effectiveness (see Chapter 2). The gap is greatest in the primary care setting, although it also is observed in specialty mental health practice. There is a need to develop case identification approaches for women in obstetrics/gynecology settings due to the high risk of recurrence in childbearing women with bipolar disorder. Little attention also has been paid to screening and mental health services for women in obstetrics/gynecology settings despite their high risk of depression (Miranda et al., 1998).

Primary care practice has been studied extensively, revealing low rates of both recognition and appropriate treatment of depression. Approximately one-third to one-half of patients with major depression go unrecognized in primary care settings (Gerber et al., 1989; Simon & Von Korff, 1995). Poor recognition leads to unnecessary and expensive diagnostic procedures, particularly in response to patients' vague somatic complaints (Callahan et al., 1996). Fewer than one-half receive antidepressant medication according to Agency for Health Care Policy Research recommendations for dosage and duration (Simon et al., 1993; Rost et al., 1994; Katon 1995, 1996; Schulberg et al., 1995; Simon & Von Korff, 1995). About 40 percent discontinue their medication on their own during the first 4 to 6 weeks of treatment, and fewer still continue their medication for the recommended period of 6 months (Simon et al., 1993). Although drug treatment is the most common strategy for treating depression in primary care practice (Olfson & Klerman, 1992; Williams et al., 1999), about one-half of primary care physicians express a preference to include counseling or therapy as a component of treatment (Meredith et al., 1994, 1996). Few primary care practitioners, however, have formal training in psychotherapy, nor do they have the time (Meredith et al., 1994, 1996). A variety of strategies have been developed to improve the management of depression in primary care settings (cited in Katon et al., 1997). These are discussed in more detail in Chapter 5 because of the special problem of recognizing and treating depression among older adults.

Another major service delivery issue focuses on the substantial number of individuals with mood disorders who go on to develop a chronic and disabling course. Their needs for a wide array of services are similar to those of individuals with schizophrenia. Many of the service delivery issues relevant to individuals with severe and persistent mood disorders are presented in the final sections of this chapter.

Schizophrenia

Overview

Our understanding of schizophrenia has evolved since its symptoms were first catalogued by German psychiatrist Emil Kraepelin in the late 19th century (Andreasen, 1997a). Even though the cause of this disorder remains elusive, its frightening symptoms and biological correlates have come to be quite well defined. Yet misconceptions abound about symptoms: schizophrenia is *neither* "split personality" *nor* "multiple personality." Furthermore, people with schizophrenia are not perpetually incoherent or psychotic (DSM-IV; Mason et al., 1997) (Table 4-6).

Schizophrenia *is* characterized by profound disruption in cognition and emotion, affecting the most fundamental human attributes: language, thought, perception, affect, and sense of self. The array of symptoms, while wide ranging, frequently includes psychotic manifestations, such as hearing internal voices or experiencing other sensations not connected to an obvious source (hallucinations) and assigning

Table 4-6. DSM-IV diagnostic criteria for schizophrenia

A. *Characteristic symptoms:* Two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):

(1) delusions

(2) hallucinations

(3) disorganized speech (e.g., frequent derailment or incoherence)

(4) grossly disorganized or catatonic behavior

(5) negative symptoms, i.e., affective flattening, alogia, or avolition

Note: Only one Criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behavior or thoughts, or two or more voices conversing with each other.

B. *Social/occupational dysfunction:* For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).

C. *Duration:* Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. *Schizoaffective and mood disorder exclusion:* Schizoaffective disorder and mood disorder with psychotic features have been ruled out because either (1) no major depressive, manic, or mixed episodes have occurred concurrently with the active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.

E. *Substance/general medical condition exclusion:* The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

F. *Relationship to a pervasive developmental disorder:* If there is a history of autistic disorder or another pervasive developmental disorder, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

unusual significance or meaning to normal events or holding fixed false personal beliefs (delusions). No single symptom is definitive for diagnosis; rather, the diagnosis encompasses a pattern of signs and symptoms, in conjunction with impaired occupational or social functioning (DSM-IV).

Symptoms are typically divided into positive and negative symptoms (see Table 4-7) because of their impact on diagnosis and treatment (Crow, 1985; Andreasen, 1995; Eaton et al., 1995; Klosterkotter et al., 1995; Maziade et al., 1996). Positive symptoms are those that appear to reflect an excess or distortion of normal functions (Peralta & Cuesta, 1998). The diagnosis of schizophrenia, according to DSM-IV, requires at least 1-month duration of two or more positive symptoms, unless hallucinations or delusions are especially bizarre, in which case one alone suffices for diagnosis. Negative symptoms are those that appear to reflect a diminution or loss of normal functions (Roy & DeVriendt, 1994; Crow, 1995; Blanchard et al., 1998). These often persist in the lives of people with schizophrenia during periods of low (or absent)

Table 4-7. Positive and negative symptoms of schizophrenia

Positive Symptoms of Schizophrenia

Delusions are firmly held erroneous beliefs due to distortions or exaggerations of reasoning and/or misinterpretations of perceptions or experiences. Delusions of being followed or watched are common, as are beliefs that comments, radio or TV programs, etc., are directing special messages directly to him/her.

Hallucinations are distortions or exaggerations of perception in any of the senses, although auditory hallucinations ("hearing voices" within, distinct from one's own thoughts) are the most common, followed by visual hallucinations.

Disorganized speech/thinking, also described as "thought disorder" or "loosening of associations," is a key aspect of schizophrenia. Disorganized thinking is usually assessed primarily based on the person's speech. Therefore, tangential, loosely associated, or incoherent speech severe enough to substantially impair effective communication is used as an indicator of thought disorder by the DSM-IV.

Grossly disorganized behavior includes difficulty in goal-directed behavior (leading to difficulties in activities in daily living), unpredictable agitation or silliness, social disinhibition, or behaviors that are bizarre to onlookers. Their purposelessness distinguishes them from unusual behavior prompted by delusional beliefs.

Catatonic behaviors are characterized by a marked decrease in reaction to the immediate surrounding environment, sometimes taking the form of motionless and apparent unawareness, rigid or bizarre postures, or aimless excess motor activity.

Other symptoms sometimes present in schizophrenia but not often enough to be definitional alone include affect inappropriate to the situation or stimuli, unusual motor behavior (pacing, rocking), depersonalization, derealization, and somatic preoccupations.

Negative Symptoms of Schizophrenia

Affective flattening is the reduction in the range and intensity of emotional expression, including facial expression, voice tone, eye contact, and body language.

Alogia, or poverty of speech, is the lessening of speech fluency and productivity, thought to reflect slowing or blocked thoughts, and often manifested as laconic, empty replies to questions.

Avolition is the reduction, difficulty, or inability to initiate and persist in goal-directed behavior; it is often mistaken for apparent disinterest.

positive symptoms. Negative symptoms are difficult to evaluate because they are not as grossly abnormal as positives ones and may be caused by a variety of other factors as well (e.g., as an adaptation to a persecutory delusion). However, advancements in diagnostic assessment tools are being made.

Diagnosis is complicated by early treatment of schizophrenia's positive symptoms. Antipsychotic medications, particularly the traditional ones, often produce side effects that closely resemble the negative symptoms of affective flattening and avolition. In addition, other negative symptoms are sometimes present in schizophrenia but not often enough to satisfy diagnostic criteria (DSM-IV): loss of usual interests or pleasures (anhedonia); disturbances of sleep and eating; dysphoric mood (depressed, anxious, irritable, or angry mood); and difficulty concentrating or focusing attention.

Currently, discussion is ongoing within the field regarding the need for a third category of symptoms for diagnosis: disorganized symptoms (Brekke et al., 1995; Cuesta & Peralta, 1995). Disorganized symptoms include thought disorder, confusion, disorientation, and memory problems. While they are listed by DSM-IV as common in schizophrenia—especially during exacerbations of positive or negative symptoms (DSM-IV)—they do not yet constitute a formal new category of symptoms. Some researchers think that a new category is not warranted because disorganized symptoms may instead reflect an underlying dysfunction common to several psychotic disorders, rather than being unique to schizophrenia (Toomey et al., 1998).

Cognitive Dysfunction

Recently there has also been more clinical and research attention on cognitive difficulties that many people with schizophrenia experience (Levin et al., 1989; Harvey et al., 1996). Cognitive problems include information processing (Cadenhead et al., 1997), abstract categorization (Keri et al., 1998), planning and regulating goal-directed behavior ("executive functions"), cognitive flexibility, attention, memory, and visual processing (Cornblatt & Keilp, 1994; Mahurin et al., 1998). These cognitive problems are especially associated with negative and disorganized symptoms but seem to be distinct (Basso et al., 1998; Brekke et al., 1995; Cuesta & Peralta, 1995; Voruganti et al., 1997), although others disagree (Roy & DeVriendt, 1994).

These cognitive problems vary from person to person and can change over time. In some situations it is unclear whether such deficits are due to the illness or to the side effects of certain neuroleptic medications (Zalewski et al., 1998). As research on brain functioning grows more sophisticated, some models posit dysfunction of fundamental cognitive processes at the *center* of schizophrenia, rather than as one of numerous symptoms (Andreasen, 1997a, 1997b; Andreasen et al., 1996). On the basis of neuropsychological and neuroanatomical data, for example, some researchers posit that schizophrenia is a disorder of the prefrontal cortex and its ability to perform the essential cognitive function of working memory (Goldman-Rakic & Selemon, 1997). Problems in such fundamental areas as paying selective attention, problem-solving, and remembering can cause serious difficulties in learning new skills (social interaction, treatment and rehabilitation) and performing daily tasks (Medalia et al., 1998); treatment of such deficits is discussed in later sections of the chapter.

Functional Impairment

The criteria for a diagnosis of schizophrenia include functional impairment in addition to the constellation of symptoms outlined above. For formal diagnosis, a person must be experiencing significant dysfunction in one or more major areas of life activities such as interpersonal relations, work or education, family life, communication, or self-care (Docherty et al., 1996; Patterson et al., 1997, 1998). These problems result from the complex of symptoms and their sequelae, but have been linked more to negative than to positive symptoms (Ho et al., 1998). They have serious economic, social, and psychological effects: unemployment, disrupted education, limited social relationships, isolation, legal involvement, family stress, and substance abuse. Such sequelae form the most distressing aspects of the illness for many people and contribute to the increased risk of suicide among people diagnosed with schizophrenia.

Cultural Variation

On first consideration, symptoms like hallucinations, delusions, and bizarre behavior seem easily defined and clearly pathological. However, increased attention to cultural variation has made it very clear that what is considered delusional in one culture may be accepted as normal in another (Lu et al., 1995). For example, among members of some cultural groups, "visions" or "voices" of religious figures are part of normal religious experience. In many communities, "seeing" or being "visited" by a recently deceased person are not unusual among family members. Therefore, labeling an experience as pathological or a psychiatric symptom can be a subtle process for the clinician with a different cultural or ethnic background from the patient; indeed, cultural variations and nuances may occur within the diverse subpopulations of a single racial, ethnic, or cultural group. Often, however, clinicians' training, skills, and views tend to reflect their own social and cultural influences.

Clinicians can misinterpret and misdiagnose patients whose cognitive style, norms of emotional expression, and social behavior are from a different culture, unless clinicians become culturally competent (see Chapter 2 and Center for Mental Health Services [CMHS], 1997). For example, clinicians may misinterpret a client's deferential avoidance of direct eye contact as a sign of withdrawal or paranoia, or a normal emotional reserve as flattened affect if they are unaware of the norms of cultural groups other than their own. There is some empirical evidence that such misinterpretations happen widely. One finding is that African-American patients are more likely than white patients to be diagnosed with severe psychotic disorders in clinical settings (Snowden & Cheung, 1990; Hu et al., 1991; Lawson et al., 1994, Strakowski et al., 1995). The overdiagnosis of psychotic disorders among African Americans is interpreted by some as evidence of clinician bias.

People with differing cultural backgrounds also may experience and exhibit true schizophrenia symptoms differently (Brekke & Barrio, 1997; Thakker & Ward, 1998). Culture shapes the content and form of positive and negative symptoms (Maslowski et al., 1998). For example, people in non-Western countries report catatonic behavior among psychiatric patients much more commonly than in the United States. How culture, societal conditions, and diagnosing tendencies among clinicians in various countries interact to create these differences is being studied but is not yet well understood.

No description of symptoms can adequately convey a person's experience of schizophrenia or other serious mental illness. Two individuals with very different internal experiences and outward presentations may be diagnosed with schizophrenia, if both meet the diagnostic criteria (Brazo & Dollfus, 1997; Kirkpatrick et al., 1998). Additionally, their symptoms and presentation may vary considerably over time (Ribeyre & Dollfus, 1996). This considerable variation (Basso et al., 1997; Sperling et al., 1997) has led to the naming of several subtypes of schizophrenia, depending on what symptoms are most prominent. Currently these are seen as variations within a single disorder. Similarly, the diagnosis is often difficult because other mental disorders share some common features. Diagnosis depends on the details of how people behave and what they report during an evaluation, the diagnostician, and variations in the illness over time. Therefore, many people receive more than one diagnostic label over the course of their involvement with mental health services. Refining the definition of schizophrenia and other serious mental illnesses to account for these individual and cultural variations remains a challenge to researchers and clinicians.

Prevalence

Studies of schizophrenia's prevalence in the general population vary depending on the way diagnostic criteria are applied and the population, setting, and method of study (Hafner & an der Heiden, 1997). In general, 1-year prevalence in adults ages 18 to 54 is estimated to be 1.3 percent (Table 4-1). Onset generally occurs during young adulthood (mid-20s for men, late-20s for women), although earlier and later onset do occur. It may be abrupt or gradual, but most people experience some early signs, such as increasing social withdrawal, loss of interests, unusual behavior, or decreases in functioning prior to the beginning of active positive symptoms. These are often the first behaviors to worry family members and friends.

Prevalence of Comorbid Medical Illness

The mortality rate in persons with schizophrenia is significantly higher than that of the general population. While elevated suicide accounts for some of the excess mortality—and is a serious problem in its own right—comorbid somatic illnesses also contribute to excess mortality. Until recently, there was little information on the prevalence of comorbid medical illnesses in people with schizophrenia (Jeste et al., 1996). A recent study was among the first to document systematically that people with schizophrenia are beset by vision and dental problems, as well as by high blood pressure, diabetes, and sexually transmitted diseases. Their self-reported lifetime rates of high blood pressure (34.1 percent), diabetes (14.9 percent), and sexually transmitted diseases (10.0 percent) are higher than those for people of similar age in the general population (Dixon et al., 1999; Dixon et al., in press-a). The reasons for excess medical comorbidity are unclear, yet medical comorbidity is independently associated with lower perceived physical health status, more severe psychosis and depression, and greater likelihood of a history of a suicide attempt (Dixon et al., 1999). These findings have important implications for improving patient management (Dixon et al., in press-b).

Course and Recovery

It is difficult to study the course of schizophrenia and other serious mental illnesses because of the changing nature of diagnosis, treatment, and social norms (Schultz et al., 1997). Overall, research indicates that schizophrenia's course over time varies considerably from person to person (DSM-IV; Wiersma et al., 1998) and varies for any one person (Moller & von Zerssen, 1995). The variability may emanate from the underlying heterogeneity of the disease process itself, as well as from biological and genetic vulnerability, neurocognitive impairments, sociocultural stressors, and personal and social factors that confer protection against stress and vulnerability (Liberman et al., 1980; Nuechterlein et al., 1994). Most individuals experience periods of symptom exacerbation and remission, while others maintain a steady level of symptoms and disability which can range from moderate to severe (Wiersma et al., 1998).

Most people experience at least one, often more, relapse after their first actively psychotic episode (Herz & Melville, 1980; Falloon, 1984; Gaebel et al., 1993; Wiersma et al., 1998). Often these are periods of more intense positive symptoms, yet the person continues to struggle with negative symptoms in between episodes (Gupta et al., 1997; Schultz et al., 1997). However, whether such exacerbations have the same degree of disabling and distressing effects each time depends greatly on the person's coping skills and support system. Over time, many people learn successful ways of managing even severe symptoms to moderate their disruptiveness to daily life (e.g., Hamera et al., 1992). Therefore, earlier years with the illness are often more difficult than later ones. Additionally, gradual onset and delays in obtaining treatment seem to raise the risk of longer episodes of acute illness over time (Wiersma et al., 1998). Early treatment with antipsychotic medications has been found to predict better long-term outcomes for people experiencing their first psychotic episode, as compared with a variety of control groups, including those in more advanced stages (Lieberman et al., 1996; Wyatt et al., 1997, 1998; Wyatt & Henter, 1998).

The course of schizophrenia is also influenced by personal orientation and motivation, and by supports in the form of skill-building assistance and rehabilitation (Lieberman et al., 1996; Awad et al., 1997; Hafner & an der Heiden, 1997). These, in turn, are heavily influenced by regional, cultural, and socioeconomic factors in addition to individual factors (Dassori et al., 1995).

Family factors also are related to the course of illness. Following hospitalization, patients who return home are more likely to relapse if their family is identified as critical, hostile, or emotionally overinvolved than if their family is not so identified (Jenkins & Karno, 1992; Bebbington & Kuipers, 1994). This is a controversial finding because it appears to blame family members (Hatfield et al., 1987). However, recent studies suggest an interaction between families and the patient (Goldstein, 1995b), suggesting that the negative emotions of some family members may be a reaction to, more than a cause of relapse in, the family member. Blaming either the family or the patient overlooks important ways both parties interact and how such interactions are associated with the course of schizophrenia. In addition, there is a need to examine what part the role of families' prosocial functioning (family warmth and family support) plays in the course of schizophrenia to identify how family factors can serve as protective factors (Lopez et al., in press).

Despite the variability, some generalizations about the long-term course of schizophrenia are possible largely on the basis of longitudinal research. A small percentage (10 percent or so) of patients seem to remain severely ill over long periods of time (Jablensky et al., 1992; Gerbaldo et al., 1995). Most do not return to their prior state of mental function. Yet several long-term studies reveal that about one-half to two-thirds of people with schizophrenia significantly improve or recover, some completely (for a review see Harding et al., 1992). These studies were important because they began to dispel the traditional view, dating back to the 19th century, that schizophrenia had a uniformly downhill course (Harding et al., 1992). Several other longitudinal studies, however, found less favorable patient outcomes with other cohorts of patients (Harrow et al., 1997). The differences in outcomes between the studies are thought to be explained on the basis of differences in patient age, length of followup, expectations about prognosis, and types of services received (Harrow et al., 1997).

The importance of a rehabilitation focus in shaping patient outcome was supported by one of the only direct comparisons between patient cohorts. The Vermont cohort consisted of the most severely affected patients from the "back wards" of the state hospital (Harding et al., 1987). As part of a statewide program of deinstitutionalization, the cohort was released in the 1950s to a hospital-based rehabilitation program and then to what was at the time an innovative, broad-based community rehabilitation program, which incorporated social, residential, and vocational components.[13] Patients' degree of recovery at followup after three decades was measured by global functional improvement and other functional measures. One-half to two-thirds of the Vermont cohort significantly improved or recovered (Harding et al., 1987). The receipt of community-based rehabilitation was considered key to their recovery on the basis of a study comparing their progress with that of a matched cohort of deinstitutionalized patients from Maine. The Maine cohort did not function as well after receiving more traditional aftercare services without a rehabilitation emphasis (DeSisto et al., 1995a, 1995b). Although the findings from the Vermont cohort, as well as those from a cohort in Switzerland (Ciompi, 1980), are widely cited by consumers as evidence of recovery from mental illness, a topic discussed in detail in Chapter 2, it bears noting that patients in the Vermont cohort represented a less rigorously defined conceptualization of schizophrenia than is common today, which may account, in part, for the more favorable outcomes.

In summary, schizophrenia does not follow a single pathway. Rather, like other mental and somatic disorders, course and recovery are determined by a constellation of biological, psychological, and sociocultural factors. That different degrees of recovery are attainable has offered hope to consumers and families.

Gender and Age at Onset

There appear to be gender differences in the course and prognosis of schizophrenia. Women are more likely than men to experience later onset, more pronounced mood symptoms, and better prognosis (DSM-IV), although the prognosis difference recently has come under question.

Current research (e.g., Hafner & an der Heiden, 1997; Hafner et al., 1998) suggests that some of the apparent gender differences in course and outcome occur because for some women schizophrenia does not develop until after menopause. This delay is thought to be related to the protective effects of estrogen, the levels of which diminish at menopause. According to this line of reasoning, men have no such delay because they lack the protective estrogen levels. Therefore, a higher proportion of men develop schizophrenia earlier.

Generally, early onset (younger than age 25 in most studies) is associated with more gradual development of symptoms, more prominent negative symptoms across the course (DSM-IV), and more neuropsychological problems (Basso et al., 1997; Symonds et al., 1997), regardless of gender. Early onset also usually involves more disruption of adult milestones, such as education, employment achievements, and long-term social relationships (Nowotny et al., 1996). People with later onset often have reached these milestones, cushioning them from disruptive sequelae and enabling better coping with symptoms (Hafner et al., 1998). Therefore, early onset (more men than women) often yields a more difficult first several years, although not necessarily a worse long-term outcome.

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[13] These are the vital components of most contemporary rehabilitation programs (see section on service delivery).

However, it must be emphasized that group probabilities do not necessarily speak to individual cases.

Etiology of Schizophrenia

The cause of schizophrenia has not yet been determined, although research points to the interaction of genetic endowment and major environmental upheaval during development of the brain. This section first discusses genetic studies and then turns to the evidence for neurodevelopmental disruption. These lines of research are beginning to converge: neurodevelopmental disruption may be the result of genetic and/or environmental stressors early in development, leading to subtle alterations in the brain. Furthermore, environmental factors later in development can either exacerbate or ameliorate expression of genetic or neurodevelopmental defects. The overarching message is that the onset and course of schizophrenia are most likely the result of an interaction between genetic and environmental influences.

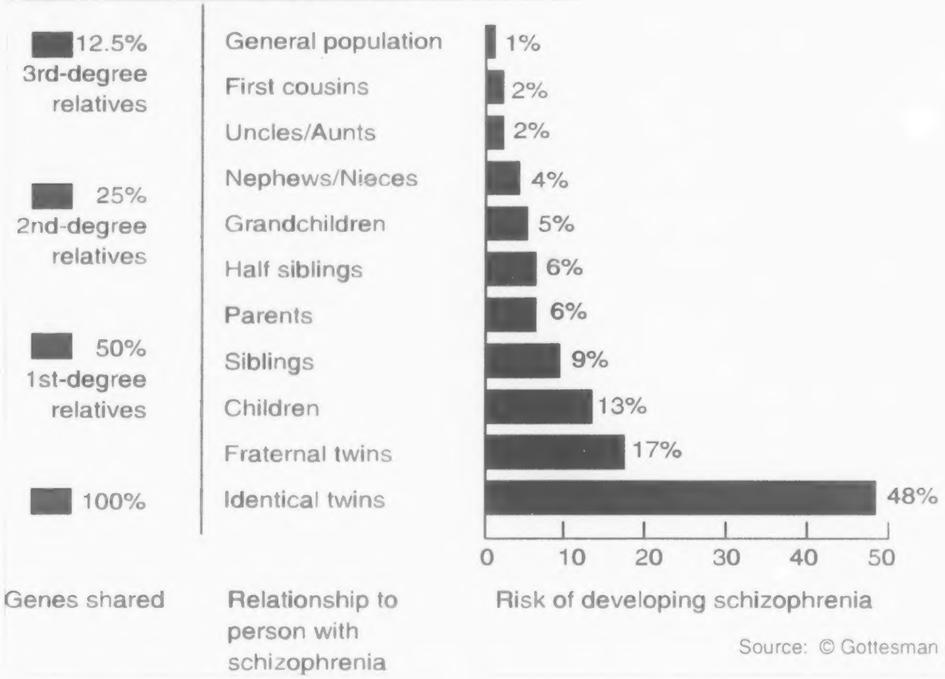
Family, twin, and adoption studies support the role of genetic influences in schizophrenia (Kendler & Diehl, 1993; McGuffin et al., 1995; Portin & Alanen, 1997). Immediate biological relatives of people with schizophrenia have about 10 times greater risk than that of the general population. Given prevalence estimates, this translates into a 5 to 10 percent lifetime risk for first-degree relatives (including children and siblings) and suggests a substantial genetic component to schizophrenia (e.g., Kety, 1987; Tsuang et al., 1991; Cannon et al., 1998). What also bolsters a genetic role are findings that the identical twin of a person with schizophrenia is at greater risk than a sibling or fraternal twin, and that adoptive relatives do not share the increased risk of biological relatives (see Figure 4-3). However, in about 40 percent of identical twins in which one is diagnosed with schizophrenia, the other never meets the diagnostic criteria. The discordance among identical twins clearly indicates that environmental factors likely also play a role (DSM-IV).

Current research proposes that schizophrenia is caused by a genetic vulnerability coupled with environmental and psychosocial stressors, the so-called diathesis-stress model (Zubin & Spring, 1977; Russo et al., 1995; Portin & Alanen, 1997). Family studies suggest that people have varying levels of inherited genetic vulnerability, from very low to very high, to schizophrenia. Whether or not the person develops schizophrenia is partly determined by this vulnerability. At the same time, the development of schizophrenia also depends on the amount and types of stresses the person experiences over time. An analogy can be drawn to diabetes by virtue of both genetic factors (e.g., family history) and behavioral factors (e.g., diet, exercise, stress) that interact to determine whether or not a given person develops diabetes. How the interaction works in schizophrenia is unknown, yet the subject of ongoing research (Murray et al., 1992; Spaulding, 1997; Jones & Cannon, 1998; van Os & Marcelis, 1998).

Despite the evidence for genetic vulnerability to schizophrenia, scientists have not yet identified the genes responsible (Kendler & Diehl, 1993; Levinson et al., 1998). The current consensus is that multiple genes are responsible (Kendler et al., 1996; Kunugi et al., 1996, 1997; Portin & Alanen, 1997; Straub et al., 1998).

Numerous brain abnormalities have been found in schizophrenia. For example, patients often have enlarged cranial ventricles (cavities in the brain that transport cerebrospinal fluid), especially the third ventricle (Weinberger, 1987; Schwarzkopf et al., 1991; Woods & Yurgelun-Todd, 1991; Dykes et al., 1992; Lieberman et al., 1993; DeQuardo et al., 1996), and decreased cerebral size (Schwarzkopf et al., 1991; Ward et al., 1996) compared with control groups. Several studies suggest this may be more common among men (Nopoulos et al., 1997) whose families do not have a history of schizophrenia (Schwarzkopf et al., 1991; Vita et al., 1994). There is also some evidence that at least some people with schizophrenia have unusual cortical laterality, with dysfunction localizing

Figure 4-3. Risk of developing schizophrenia.



Source: © Gottesman (1991).

to the left hemisphere (Braun et al., 1995). To explain laterality, some have proposed a prenatal injury or insult at the time of left hemisphere development, which normally lags behind that of the right hemisphere (Bracha, 1991).

The anatomical abnormalities found in different parts of the brain tend to correlate with schizophrenia's positive symptoms (Barta et al., 1990; Shenton et al., 1992, Bogerts et al., 1993; Wible et al., 1995) and negative symptoms (Buchanan et al., 1993). Positive symptoms are often linked to temporal lobe dysfunction, as shown by imaging studies that utilize blood flow and glucose metabolism. Such dysfunction possibly is related to abnormal phospholipid metabolism (Fukuzako et al., 1996). Disorganized speech (taken to reflect disorganized thinking) has been associated with abnormalities in brain regions associated with speech regulation (McGuire et al., 1998). Negative and cognitive symptoms, especially those related to volition and planning, are commonly associated with prefrontal lobe dysfunction (Capleton, 1996; Abbruzzese et al., 1997; Mattson et al., 1997). This is perhaps related to unusual neuronal density (Selemon et al., 1998) and may be more prevalent among patients whose families have a history of schizophrenia than those whose do not (Sautter et al., 1995). However, mapping patients' symptoms with brain regions is complex and variable. Researchers believe that the dysfunctions are present in brain circuitry rather than in one or two localized areas of the brain (Andreasen et al., 1997, 1998; Wiser et al., 1998).

Excessive levels of the neurotransmitter dopamine have long been implicated in schizophrenia, although it is unclear whether the excess is a primary cause of schizophrenia or a result of a more fundamental dysfunction. More recent evidence implicates much greater complexity in the dysregulation of dopamine and other neurotransmitter systems (Grace, 1991, 1992; Olie & Bayle, 1997). Some of this research ties schizophrenia to certain variations in dopamine receptors (Nakamura et al., 1995; Serretti et al., 1998), while other research focuses on the serotonin system (Inayama et al., 1996). However, it must be emphasized that in many cases it is possible that perturbations in neurotransmitter systems may result from complications of schizophrenia, or its treatment, rather than from its causes (Csernansky & Grace, 1998).

The "stressors" investigated in schizophrenia research include a wide range of biological, environmental, psychological, and social factors. There is consistent evidence that prenatal stressors are associated with increased risk of the child developing schizophrenia in adulthood, although the mechanisms for these associations are unexplained. Some interesting preliminary research suggests risk factors include maternal prenatal poverty (Cohen, 1993), poor nutrition (Susser & Lin, 1992; Susser et al., 1996, 1998), and depression (Jones et al., 1998). Other stressors are exposure to influenza outbreaks (Mednick et al., 1988; Adams et al., 1993; Rantakallio et al., 1997), war zone exposure (van Os & Selten, 1998), and Rh-factor incompatibility (Hollister, 1996). Their variety suggests other stressors might also be risk factors, under the general rubric of "maternal stress."

As a result of such stresses, newborns of low birth weight and short gestation have been linked to increased risk of later developing schizophrenia (Jones et al., 1998), as have delivery complications (Hultman et al., 1997; Jones & Cannon, 1998) and other early developmental problems (Brixey et al., 1993; Ellenbroek & Cools, 1998; Portin & Alanen, 1998; Preti et al., 1998). Among children, especially infants, viral central nervous system infections may be associated with greater risk (Rantakallio et al., 1997; Iwahashi et al., 1998), thereby explaining links between schizophrenia and being born or raised in crowded conditions (Torrey & Yolken, 1998) or during the flu-prone winter and spring months (Castrogiovanni et al., 1998). However, support for these hypotheses is inconsistent and incomplete (Yolken & Torrey, 1995). In fact, it is possible that prenatal and obstetric complications associated with schizophrenia could reflect already disrupted fetal development, rather than being causal themselves (Lipska & Weinberger, 1997). More generally, across the life span, the chronic stresses of poverty (Cohen, 1993; Saraceno & Barbui, 1997) and some facets of minority social status appear to alter the course of schizophrenia.

Presently, it is unclear whether and how these risks contribute to the diathesis-stress interaction for any one person because specific causes may differ (Onstad et al., 1991; Cardno & Farmer, 1995; Tsuang & Faraone, 1995; Miller, 1996). Although genetic vulnerability is difficult to control, certain other important factors can be addressed with current knowledge. An awareness of stressors that increase the likelihood of genetic vulnerability being actualized supports preventive strategies, such as good prenatal health care and nutrition. Furthermore, since life stresses can exacerbate the course of the illness, access to good quality services and social supports, as well as attention to relapse prevention interventions, can have beneficial effects on longer term outcome (Wiersma et al., 1998).

At the same time, researchers and clinicians are striving to integrate findings concerning both diathesis and stress into models of how schizophrenia develops (Andreasen, 1997b). Not only does brain biology influence behavior and experience, but behavior and experience mold brain biology as well. One promising integrative model is the neurodevelopmental theory of schizophrenia developed by Weinberger and others (Murray & Lewis, 1987; Weinberger, 1987, 1995; Bloom, 1993; Weinberger & Lipska, 1995; Lipska & Weinberger, 1997). It posits that schizophrenia develops from "a subtle defect in cerebral development that disrupts late-maturing, highly evolved neocortical functions, and fully manifests itself years later in adult life" (Lipska & Weinberger, 1997; see also Susser et al., 1998).

The nature of the defect, which has not been identified, may be a product of a pre- or neonatal insult to the brain. Further support for the neurodevelopmental theory comes from abnormalities in brain structure that have long been found in people with schizophrenia. Such findings have been interpreted to reflect abnormal neuronal migration in early development (Jakob & Beckmann, 1986; Arnold et al., 1991; Akbarian et al., 1993; Falkai et al., 1995). Researchers have developed animal models of early neurodevelopmental dysfunctions that manifest in later behavioral and functional deficits (Geyer et al., 1993; Lipska & Weinberger, 1993; Wilkinson et al., 1994;

Table 4-8. Selected treatment recommendations, Schizophrenia Patient Outcomes Research Team

Recommendation 1. Antipsychotic medications, other than clozapine, should be used as the first-line treatment to reduce psychotic symptoms for persons experiencing an acute symptom episode of schizophrenia.

Recommendation 2. The dosage of antipsychotic medication for an acute symptom episode should be in the range of 300–1,000 chlorpromazine (CPZ) equivalents per day for a minimum of 6 weeks. Reasons for dosages outside this range should be justified. The minimum effective dose should be used.

Recommendation 8. Persons who experience acute symptom relief with an antipsychotic medication should continue to receive this medication for at least 1 year subsequent to symptom stabilization to reduce the risk of relapse or worsening of positive symptoms.

Recommendation 9. The maintenance dosage of antipsychotic medication should be in the range of 300–600 CPZ equivalents (oral or depot) per day.

Recommendation 12. Depot antipsychotic maintenance therapy should be strongly considered for persons who have difficulty complying with oral medication or who prefer the depot regimen.

Recommendation 23. Individual and group therapies employing well-specified combinations of support, education, and behavioral and cognitive skills training approaches designed to address the specific deficits of persons with schizophrenia should be offered over time to improve functioning and enhance other target problems, such as medication noncompliance.

Recommendation 24. Patients who have ongoing contact with their families should be offered a family psychosocial intervention that spans at least 9 months and that provides a combination of education about the illness, family support, crisis intervention, and problem-solving skills training. Such interventions should also be offered to nonfamily members.

Recommendation 27. Selected persons with schizophrenia should be offered vocational services.*

Recommendation 29. Systems of care serving persons with schizophrenia who are high users should include ACT and ACM programs.

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* Edited

Source: Lehman & Steinwachs, 1998a, 1998b.

Lipskaet al., 1995) and are influenced by genetics (de Kloet et al., 1996; Zaharia et al., 1996). As promising as these theories are, the causes and mechanisms of schizophrenia remain unknown. Nonetheless, research has uncovered several types of treatment for schizophrenia that are effective in reducing symptoms and functional impairments.

Interventions

The treatment of schizophrenia has advanced considerably in recent years. A battery of treatments has become available to ameliorate symptoms, to improve quality of life, and to restore productive lives. Treatment and other service interventions often are linked to the clinical phases of schizophrenia: acute phase, stabilizing phase, stable (or maintenance) phase, and recovery phase. Where possible, this report ties available data to these treatment phases.

Optimal treatment across all phases of treatment includes some form of pharmacotherapy with antipsychotic medication, usually combined with a variety of psychosocial interventions. Psychosocial interventions include supportive psychotherapy, and family psychoeducational interventions, as well as psychosocial and vocational rehabilitation. The treatment of individuals with schizophrenia who are high service users should be orchestrated by an interdisciplinary treatment team to ensure continuity of services (i.e., assertive community treatment, which is discussed below). Others may benefit from less intensive forms of case management and various self-help and consumer-operated services, described later. It is also important to assist individuals with schizophrenia in meeting their many related needs, such as for supported housing, transportation, and general medical care. These are among the 30 pivotal treatment recommendations of the Agency for Health Care Policy and Research- and NIMH-sponsored Schizophrenia Patient Outcomes Research Team (PORT), which developed its recommendations on the basis of a comprehensive review of the treatment outcomes literature (Lehman & Steinwachs, 1998a). Table 4-8 contains a distillation of key recommendations.

Although the Schizophrenia PORT study recommendations are grounded in research such as that reviewed in the following paragraphs, it is noteworthy that treatment practices fail to adhere to these recommendations, with conformance generally falling below 50 percent (Lehman & Steinwachs, 1998b). The disturbing gap between knowledge and practice is discussed later in this chapter. Many barriers exist in the transfer of information about treatment and evidence-based practice to clinicians, family members, and service users.

Pharmacotherapy

Pharmacotherapies are the most extensively evaluated intervention for schizophrenia. The conventional or older antipsychotic medications (e.g., chlorpromazine, haloperidol, fluphenazine, molindone) and the more recently developed medications (e.g., clozapine, risperidone, olanzapine, quetiapine, sertindole) are used to reduce the positive symptoms of schizophrenia. The newer medications, often called atypical because they have a different mechanism action than their predecessors, also appear in preliminary studies to be more effective against negative symptoms, display fewer side effects, and show promise for treating people for whom older medications are ineffective (Ballus, 1997). Their introduction has created more treatment options for people with schizophrenia and other serious mental illnesses. Although the newer, more broadly effective medications have increased hopes for recovery, they also have resulted in greater treatment complexity for patients and providers alike (Fenton & Kane, 1997).

Conventional antipsychotics have been shown to be highly effective both in treating acute symptom episodes and in long-term maintenance and prevention of relapse (Cole & Davis, 1969; Davis et al., 1989; Kane, 1992). Across many studies, positive symptoms improved in about 70 percent of patients, compared with only 25 percent improvement in placebo groups (Kane, 1989; Kane & Marder, 1993). Their common mechanism of action is by blocking dopamine D_2 receptors, and their therapeutic effects are presumably due to D_2 blockade in the mesolimbic system (Dixon et al., 1995).

For acute symptom episodes, treatment recommendations call for dosages of antipsychotic medication in the range of 300 to 1,000 "chlorpromazine equivalents"[14] per day (Lehman & Steinwachs, 1998b). Among patients discharged from inpatient units whose dosage fell outside of this range, minority patients often are much more likely than Caucasian patients to be on a higher dose (> 1,000 chlorpromazine equivalents) (Lehman & Steinwachs, 1998b). Such dosing patterns run counter to evidence that a higher proportion of minority patients, because of lower rates of drug metabolism, may require lower doses of antipsychotics.

Dosage studies have found that moderate levels (300 to 750 chlorpromazine equivalents daily for acute episodes, 300 to 600 for maintenance, although many people require less than 300) are more effective for positive symptom reduction over the long run than very high ("loading"), intermittent, or very low doses (Donlon et al., 1978, 1980; Nehorsky et al., 1981; Baldessarini et al., 1990; Levinson et al., 1990; Van Putten et al., 1990, 1992; Rifkin et al., 1991). Very low

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[14] A chlorpromazine equivalent is a measure in milligrams of antipsychotic medication doses indexed to the potency of a standard dosage of chlorpromazine, one of the earliest, most widely used antipsychotic medications.

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and intermittent dosing substantially increases the risk of relapse, while rapid loading and very high doses greatly increase adverse effects (Davis et al., 1989), although medication programs must be tailored to individual needs. On conventional neuroleptics, patients experience symptom reduction over the first 5 to 10 weeks of treatment, with more gradual improvement sometimes continuing for more than double that time (Baldessarini et al., 1990). The older medications are occasionally found to reduce some negative symptoms as well, although it is impossible to tell from existing research if this is a primary or secondary effect of reduced positive symptoms (Davis et al., 1989; Cassens et al., 1990).

Apart from their minimal effects on negative symptoms, the greatest problem with conventional neuroleptic medications is their pervasive, uncomfortable, and sometimes disabling and dangerous side effects. The spectrum of side effects is broad (Davis et al., 1989; Casey, 1997), yet the most common and troubling are extrapyramidal effects such as acute dystonia, parkinsonism, and tardive dyskinesia (Chakos et al., 1996; Yuen et al., 1996; Trugman, 1998) andakathisia (Kane, 1985).[15] Side effects are evident in an estimated 40 percent of patients, but pinpointing their prevalence is complicated by the vagaries of diagnosis, length of prescription and observation, and variability across individuals and medications. Rare side effects (seizures, paradoxical exacerbation of psychotic symptoms, neuroleptic malignant syndrome) also can be devastating.

Acute dystonia, parkinsonism, dyskinesias, and akathisia are usually treated by lowering the doses of neuroleptics and/or using adjunctive anticholinergic, antiparkinsonian medications (e.g., benztropine). Because these side effects can be mistaken for core psychotic symptoms, the neuroleptic dose is often increased, rather than decreased, exacerbating the side effects. Many other side effects such as attention and vigilance problems, sleepiness, blurry vision, dry mouth, and constipation are worse in the initial weeks of treatment and usually taper off as a person adjusts to the medication. However, the discomfort and disability of the initial weeks are intolerably disruptive to some individuals. Dosages can be individualized to minimize side effects while maximizing benefit.

Efficacy data on the newer antipsychotics indicate that they are as efficacious as the older agents at reducing positive symptoms and carry fewer side effects. They also offer important additional advantages for some who have had treatment-resistant schizophrenia (Kane, 1996, 1997; Vanelle, 1997; van Os et al., 1997; Andersson et al., 1998).

The prototype of the newer medications, clozapine, has been found effective for about 30 to 50 percent of treatment-resistant patients (Kane & Marder, 1993; Lieberman et al., 1994; Buchanan, 1995; Kane & McGlashan, 1995; Kane, 1996), as well as for patients who have responded to previous medications. Clozapine also seems to help secondary depression and anxiety, and perhaps the negative symptoms of schizophrenia (Buchanan, 1995). Clozapine not only has a very low incidence of tardive dyskinesia (Barnes & McPhillips, 1998) but may also show some promise as its treatment (Walters et al., 1997). However, the use of clozapine was constrained for many years in the United States because of findings that in about 1 percent of patients it causes a potentially fatal blood condition: agranulocytosis, a loss of white blood cells that fight infection. Because agranulocytosis is reversible if detected early, frequent (weekly) blood monitoring is critical (Lamarque, 1996; Meltzer, 1997). Although effective safeguards exist, use of clozapine tends to be limited to those who are unresponsive to, or cannot tolerate, other antipsychotics. The Veterans' Administration sponsored the largest cost-effectiveness study to date of clozapine, comparing it to haloperidol. Studies by Rosenheck and his collaborators (1997, 1998b, 1999) replicated previous findings that clozapine was more effective than haloperidol in treating positive and negative symptoms and had fewer extrapyramidal side effects. In addition to its direct pharmacologic effect, the investigators found that clozapine enhances participation in psychosocial treatments, which augments its overall clinical effectiveness (Rosenheck et al., 1998b). Savings associated with use of clozapine were particularly significant among study participants who had averaged 215 inpatient hospital days in the year prior to the study (Rosenheck et al., 1998b).

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[15] Acute dystonia is involuntary muscle spasms resulting in abnormal and usually painful body positions. Parkinsonism is defined by tremors, muscle rigidity, and stuporous appearance. Dyskinesias are involuntary repetitive movements, often of the mouth, face, or hands, and akathisia is painful muscular restlessness requiring the person to move constantly.

Increasing numbers of patients with schizophrenia receive newer agents like risperidone (Smith et al., 1996a; Foster & Goa, 1998), olanzapine (Bymaster et al., 1997), and quetiapine (Wetzel et al., 1995; Gunasekara & Spencer, 1998). They have replaced the older antipsychotics in many cases because they cause fewer side effects at therapeutic levels (Umbricht & Kane, 1995) and do not require clozapine's close monitoring. Their effects on negative schizophrenia symptoms are currently being evaluated and hold some promise, as do their effects on some cognitive dysfunctions (Gallhofer et al., 1996; Green et al., 1997; Kern et al., 1998). Furthermore, current cost analyses find these newer medications at least cost-neutral and sometimes more cost-effective in the long run than older agents, despite being more expensive per pill (Loebel et al., 1998).

Thus, as a whole, there is evidence that the newer antipsychotics are more clinically advantageous than the older ones due to the combination of their effective treatment of positive (and perhaps negative) symptoms, their treatment of ancillary symptoms such as anxiety and depression, and their more favorable side effect profile (Lieberman, 1993, 1996; Fleischhacker & Hummer, 1997; Shore, 1998). Having fewer side effects generally results in better compliance with the medication, although atypical side effects can include sedation, weight gain, sexual dysfunction, and other dose-related discomforts (Casey, 1997; Hasan & Buckley, 1998). Although the newer agents have less adverse impact on fecundity, so that more women with schizophrenia can conceive, there are very little data to address the impact of treatment on pregnancy and lactation. While it is not clear whether the newer medications directly lessen the functional disabilities that usually accompany schizophrenia, they may improve a person's quality of life (Lehman, 1996) and responsiveness to psychosocial, rehabilitation, and therapeutic interventions (Buckley, 1997). Effectiveness in real-world settings may be substantially lower than efficacy in clinical trials, possibly due to patient heterogeneity, prescribing practices, and noncompliance (Dixon et al., 1995).

Ethnopsychopharmacology

Growing awareness that ethnicity and culture influence patients' response to medications has catapulted to prominence the field of ethnopharmacology. In the past decade, studies have demonstrated that psychiatric medications interact with patient ethnicity in multiple ways, with response to the same medication and dose varying by patient ethnicity (Frackiewicz et al., 1997). For example, due to racial and ethnic variation in pharmacokinetics, Asians and Hispanics with schizophrenia may require lower doses of antipsychotics than Caucasians to achieve the same blood levels (Collazo et al., 1996; Ramirez, 1996; Ruiz et al., 1996). Pharmacokinetics and pharmacodynamics also vary across other ethnic groups.[16] Racial and ethnic variation likely stem from a combination of genetic and psychosocial factors, such as diet and health behaviors (Lin et al., 1995).

At the same time, it is possible that the documented medication differences are the result of underlying biological mechanisms of mental illness related to ethnicity, culture, and gender variations. Additionally, the effects of psychotropic medications may be interpreted differently by culture (Lewis et al., 1980). Although knowledge in these areas is incomplete, it is important to consider cultural patterns in dosing decisions and medication management, as well as risks of side effects and tardive dyskinesia. Furthermore, studies suggest that medication differences among African American people diagnosed with schizophrenia may reflect clinician biases in diagnosis and prescription practices more than differences in medication metabolism or health behaviors alone (Frackiewicz et al., 1997).

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[16] For Caucasian, Hispanic, Asian, Africian-Americans variations, see Frackiewicz et al., 1997; Chinese-Jann et al., 1992; black, white, Chinese, Mexican American-Lam et al., 1995; Lin et al., 1995)

Psychosocial Treatments

Psychosocial treatments are vital complements to medication for individuals with schizophrenia. They help patients maximize functioning and recovery. The PORT treatment recommendations, as noted earlier, stipulate that patients should receive pharmacotherapy in conjunction with supportive psychotherapy, family treatment, psychosocial rehabilitation and skill development, and vocational rehabilitation (Lehman & Steinwachs, 1998a). In the active phase of illness, medication enables patients to be more receptive to psychosocial treatments. During periods of remission, when maintenance medication is still recommended, psychosocial treatments continue to help patients to improve quality of life. Psychosocial treatments assume even greater importance for patients who do not respond to, cannot tolerate, or refuse to take medications. Several decades ago, psychosocial programs were developed that used little or no medication (Mosher, 1999). For a highly selected group of patients at the beginning of their first acute episode of schizophrenia, these programs were reported effective (Mosher & Menn, 1978). Most patients, however, do not meet the selection criteria employed in this study. Few such programs are currently operating (Mosher, 1999), and treatment with antipsychotic medication is recommended in conjunction with psychosocial treatments (Lehman & Steinwachs, 1998a).

Psychotherapy

Outcomes of individual and group therapies have been studied for people with schizophrenia, although not extensively and not in relation to current managed care practices. Overall, it is clear that individual and group therapies that focus on practical life problems associated with schizophrenia (e.g., life skills training) are superior to psychodynamically oriented therapies (Scott & Dixon, 1995a). Psychodynamically oriented therapies are considered to be potentially harmful; therefore, their use is not recommended (Lehman, 1997). Individual, group, or family therapies that combine support, education, and behavioral and cognitive skills, and that address specific challenges, can help clients cope with their illness and improve their functioning, quality of life, and degree of social integration. However, the optimum length of therapy seems to be longer than that afforded by "brief therapy" (Gunderson et al., 1984; Stanton et al., 1984; Hogarty et al., 1997). Additionally, certain targeted therapeutic interventions may be useful in addressing specific symptoms (Drury et al., 1996; Jensen & Kane, 1996). Certain subgroups of clients appear to find different types of therapy more or less useful than others (Scott & Dixon, 1995a).

Family Interventions

Several professionally operated family intervention programs have been developed to help the family member with severe mental illness (e.g., Hogarty et al., 1987; Cazzullo et al., 1989; Mari & Streiner, 1994; McFarlane, 1997). Randomized trials have been conducted for interventions that educate families about schizophrenia, provide support and crisis intervention, and offer training in effective problem solving and communication. These interventions have strongly and consistently demonstrated their value in preventing or delaying symptom relapse and appear to improve the patient's overall functioning and family well-being (Goldstein et al., 1978; Falloon et al., 1985; Strachan, 1986; Lam, 1991; Tarrier et al., 1994; Goldstein 1995a; Penn & Mueser, 1996). Research has suggested that groups of multiple families are more effective and less expensive than individual family interventions (McFarlane et al., 1995). Incorporating family religious and ethnic background may prove useful in family interventions (Guarnaccia et al., 1992). Family self-help groups are discussed subsequently in this chapter.

Psychosocial Rehabilitation and Skills Development

Psychosocial skills training strives to teach clients verbal and nonverbal interpersonal skills and competencies to live successfully in community settings. Skills or tasks are divided into small, simple behavioral elements that the client then learns, practices, and puts together. Currently, there is a growing addition of cognitive skill remediation to rehabilitation programs that have focused on social skills training (Bellack et al., 1989; Bellack & Mueser, 1993; Scott & Dixon, 1995a). As one example of the scope of such programs, the program examined by Liberman and co-workers (1998) focused on four skill areas: medication management, symptom management, recreation for leisure, and basic conversation skills. Each area was addressed through concrete topics, with the basic conversation skills module, for example, consisting of active listening skills, initiating conversations, maintaining conversations, terminating conversations, and putting it all together.

The evolution of psychosocial skills training is important yet incomplete. A review in the mid-1990s concluded that its overall impact on social, cognitive, or vocational functioning is modest, and it remains unclear whether these gains are maintained after the training is over and can be used in real-life situations (Scott & Dixon, 1995a). However, a more recent study found greater independent living skills among clients who had received skills training during a 2-year followup of everyday community functioning (Liberman et al., 1998). Several others agree that skills training is effective for specific behavioral outcomes (Marder et al., 1996; Penn & Mueser, 1996). Specific symptom profiles may also influence how effective skills training is for a given person (Kopelowicz et al., 1997). Furthermore, Medalia and coworkers (1998) report recent success adapting cognitive rehabilitation techniques, originally developed for survivors of serious head injuries, for people with schizophrenia, but long-term effects and generalizability have not been determined. This exemplifies both the progress and the need for further refinement of this intervention (Smith et al., 1996b).

In a recent review article, a team of researchers concluded that the most potent rehabilitation programs (1) establish direct, behavioral goals; (2) are oriented to specific effects on related outcomes; (3) focus on long-term interventions; (4) occur within or close to clients' naturally preferred settings; and (5) combine skills training with an array of social and environmental supports. They also note that most programs do not contain all of these elements, but most are much improved over previous eras (Mueser et al., 1997b).

There are a host of multi-component psychosocial rehabilitation *services* that combine pharmacologic treatment, independent living and social skills training, psychological support to clients and their families, housing, vocational rehabilitation, social support and network enhancement, and access to leisure activities (World Health Organization [WHO], 1997). These are discussed in the later section on service delivery.

Coping and Self-Monitoring

An important goal of recovery and the consumer movement is to enable patients themselves to participate more actively in their own treatment. While complete remission of all symptoms is unlikely for the majority, most can and do learn skills and techniques over time that they can use to manage distressing symptoms and the effects of the illness. Often, better skills in coping and monitoring one's own health status occurs simply through experience. However, the growth of self-help and the development of recovery models for serious mental illnesses has spawned interventions that purposefully teach and encourage active coping on the part of clients and their families. Controlled research is sparse (Penn & Mueser, 1996), except in the area of relapse prevention.

For example, some people find it very useful to pay attention to their own warning signs of relapse or symptom exacerbation, so that additional coping practices, supports, or interventions can be put into place. Norman and Malla (1995) conclude that there is not a standardized set of signs that predict relapse, but that some individuals have and get to know their own reasonably consistent patterns. Herz and Lamberti (1995) agree that many people experience predictable signs, although whether a relapse occurs depends on many factors besides the signs themselves. Therefore, the risk and magnitude of relapse can be reduced by monitoring early symptoms and intervening when they emerge (Herz & Lamberti, 1995). Watching for such signs is recommended for consumers, family members, and clinicians (Jorgensen, 1998). Specific training programs for teaching individuals with schizophrenia to identify the warning signs of relapse and to develop relapse prevention plans have been shown to be effective (Liberman et al., 1998).

Vocational Rehabilitation

Unemployment is pervasive among people with serious and persistent mental illness. Employment is valued highly by the general public and by people with schizophrenia alike because it generates financial independence, social status, contact with other people, structured time and goals, and opportunities for personal achievement and community contribution (Mowbray et al., 1997). These attributes of employment, combined with the self-esteem and personal purpose that it engenders, make vocational rehabilitation a prominent facet of treatment for serious mental illnesses. Vocational rehabilitation is especially important because early adult onset often disrupts education and employment history.

Controlled studies of vocational rehabilitation interventions have shown mixed results (Lehman, 1995, 1998; Cook & Jonikas, 1996). Although such programs do seem to increase work-related activities while people are engaged in them, the gains do not seem to be translated into more *independent* employment once services cease. This has led to the conclusion that ongoing support is needed for many individuals with schizophrenia who wish to work in competitive employment (Wehman, 1988). Recent controlled studies have shown the effectiveness of this newer type of so-called supported employment models, which emphasize rapid placement in a real job setting and strong support from a job coach to learn, adapt, and maintain the position (Drake et al., 1994, 1996; Bond et al., 1997). These models, which are growing in use, strike a dynamic balance between being supportive yet challenging in order to avoid clients' dependency and maximize their growth (Mowbray et al., 1997).

As vocational rehabilitation has moved away from sheltered workshops and toward supported employment models, the Americans With Disabilities Act of 1990 has helped to open jobs and educate employers about reasonable accommodations for people with psychiatric disabilities (Mechanic, 1998; Scheid, 1998). Additionally, innovations like client-run and client-owned vocational programs and independent businesses have begun to be developed on a larger scale (Rowland et al., 1993; Miller & Miller, 1997). These innovations are part of a larger movement of consumer involvement in the provision of services for people with mental illness (see Chapter 2).

Service Delivery

The organization of services for adults with severe mental disorders is the linchpin of effective treatment. Since many mental disorders are best treated by a constellation of medical and psychosocial services, it is not just the services in isolation, but the delivery system as a whole, that dictates the outcome of treatment (Goldman, 1998b). Access to a delivery system is critical for individuals with severe mental illness not only for treatment of symptoms but also to achieve a measure of community participation.

Among the fundamental elements of effective service delivery are integrated community-based services, continuity of providers and treatments, and culturally sensitive and high-quality, empowering services (Mowbray et al., 1997; Lehman & Steinwachs, 1998a). Effective service delivery also requires support from the social welfare system in the form of housing, job opportunities, welfare, and transportation (Goldman, 1998a), issues that are discussed in the final section of this chapter.

What models of service delivery are most effective? This section strives to answer this question by focusing on models of service delivery for individuals with severe and persistent mental disorders, including severe depression and bipolar disorder, as well as schizophrenia. Although adults with mental illness in midlife confront many service delivery issues—for example, the problem of proper identification and treatment of depression in primary care settings—those who are most disabled by mental disorders encounter special service delivery problems. The focus on the most disabled is warranted for three reasons: (1) Society has a special obligation to those who are most impaired and consequently are the "least well off" (Callahan, 1999; Goldman, 1999; Rosenheck, 1999); (2) the body of research on mental health services delivery for this population is extensive; and (3) existing service systems are seriously deficient.

The deficiency of existing service systems is best documented for individuals with schizophrenia. The *majority* of people with schizophrenia do not receive the treatment and support they need, according to a groundbreaking finding of PORT (Lehman & Steinwachs, 1998a). PORT, as noted earlier, developed a series of basic treatment recommendations after reviewing hundreds of outcome studies. It proceeded to determine whether these recommendations were being met by examining current patterns of care in two states in the United States.

Among those with severe mental disorders, any number of special populations might have been the focus for this section. These special populations have severe mental disorders and HIV/AIDS (Cournos & McKinnon, 1997); are involved in the criminal justice system (Abram & Teplin, 1991; CMHS, 1995; Lamb & Weinberger, 1998); or have somatic health problems (Berren et al., 1994; Felker et al., 1996; Brown, 1997). Although some of what follows may be relevant to the unique needs of each of these groups, the evidence base is less well developed.

The remainder of this section focuses on case management, assertive community treatment, psychosocial rehabilitation services, inpatient hospitalization and community alternatives for crisis care, and combined treatment for people with the dual diagnosis of substance abuse and severe mental illness.

Case Management

The purpose of case management is to coordinate service delivery and to ensure continuity and integration of services. Case managers engage in a variety of activities, ranging from simple roles in locating services to more intensive roles in rehabilitation and clinical care. The less intensive models of case management seem to increase clients' links to, and use of, other mental health services at relatively modest cost. More intensive models also appear to help clients to increase daily-task functioning, residential stability, and independence, and to reduce their hospitalizations (Borland et al., 1989; Mueser et al., 1998a). Overall, models that focus on specific outcomes are more effective than those with global, vaguely defined goals (Attkisson et al., 1992).

More programs are beginning to employ mental health consumers as case managers in their multidisciplinary staff. Results have been positive, but the programs are challenging to implement and require ongoing supervision as do all case management programs (Mowbray et al., 1996). In a controlled study, clients served by case management teams, along with consumers as peer-specialists, displayed greater gains in several areas of quality of life and greater reductions in major life problems, as compared with two comparison groups of clients served by case management teams without peer-specialists (Felton et al., 1995). One randomized clinical trial compared case management teams wholly staffed by consumers versus case management teams staffed by nonconsumers. The study (at 1-year and 2-year followup) found that clients improved equally well with consumer and nonconsumer case managers (Solomon & Draine, 1995). In this series of studies, the case management teams were part of an intensive program of services known as assertive community treatment.

Assertive Community Treatment

Assertive community treatment is an intensive approach to the treatment of people with serious mental illnesses that relies on provision of a comprehensive array of services in the community. The model originated in the late 1970s with the Program of Assertive Community Treatment in Madison, Wisconsin (Stein & Test, 1980). Fueled by deinstitutionalization and the vital need for community-based services, a multidisciplinary team serving psychiatric inpatients adapted its role to patients in the community. For this reason, assertive community treatment often is likened to a "hospital without walls."

The hallmark of assertive community treatment is an interdisciplinary team of usually 10 to 12 professionals, including case managers, a psychiatrist, several nurses and social workers, vocational specialists, and more recently includes substance abuse treatment specialists and peer specialists. Assertive community treatment also possesses these features: coverage 24 hours, 7 days per week; comprehensive treatment planning; ongoing responsibility; staff continuity; and small caseloads, most commonly with 1 staff member for every 10 clients (Scott & Dixon, 1995b). Because of the intensity of services, assertive community treatment is most cost-effective when targeted to individuals with the greatest service need, particularly those with a history of multiple hospitalizations (Scott & Dixon, 1995b; Lehman & Steinwachs et al., 1998a).

Randomized controlled trials have demonstrated that assertive community treatment and similar models of intensive case management substantially reduce inpatient service use, promote continuity of outpatient care, and increase community tenure and residence stability for people with serious mental illnesses (Stein & Test, 1980; Bond et al., 1995; Lehman, 1998; Mueser et al., 1998a). Among the beneficiaries are homeless individuals and those with substance abuse problems and mental disorders. Evidence of effectiveness is weaker for other outcomes (e.g., social integration, employment) and for amelioration of substance abuse problems associated with schizophrenia, particularly when combined treatment is not offered (Mueser et al., 1998b). Assertive community treatment models are generally popular with clients (Stein & Test, 1980) and family members (Flynn, 1998). There also are some preliminary results suggesting that employing peer (i.e., consumer) or family outreach workers on the multidisciplinary assertive community treatment teams increases positive outcomes (Dixon et al.,1997, 1998) and creates more positive attitudes among team members toward people with mental illnesses.

Psychosocial Rehabilitation Services

As noted above, there are a range of multicomponent programs called psychosocial rehabilitation services that are distinct from the single component skills training interventions described in the section on interventions for schizophrenia. These psychosocial rehabilitation programs combine pharmacologic treatment, independent living and social skills training, psychological support to clients and their families, housing, vocational rehabilitation, social support and network enhancement, and access to leisure activities (WHO, 1997). Randomized clinical trials have shown that psychosocial rehabilitation recipients experience fewer and shorter hospitalizations than comparison groups in traditional outpatient treatment (Dincin & Witheridge, 1982; Bell & Ryan, 1984). In addition, recipients are more likely to be employed (Bond & Dincin, 1986). Cook & Jonikas (1996) review the outcomes of a wide range of psychosocial rehabilitation programs, including Fairweather lodges (Fairweather et al., 1969) and psychosocial clubhouses (Dincin, 1975), some of which were demonstrated as effective 20 and 30 years ago but have not been widely implemented.

Inpatient Hospitalization and Community Alternatives for Crisis Care

The role of psychiatric hospitalization has changed greatly over recent decades, stemming from the recognition of poor and occasionally abusive conditions, excessive patient dependency, and patients' loss of connection to the community (Wing, 1962; Gruenberg, 1974). More recent evolution in hospitalization traces to changes in the financing of care and the introduction of new medications (Appleby et al., 1993; Bezold et al., 1996). Community-based alternatives for crisis care services began to flourish in lieu of hospitalization (Fenton et al., 1998; Mosher, 1999).

The new priorities of psychiatric hospitalization focus on ameliorating the risk of danger to self or others in those circumstances in which dangerous behavior is associated with mental disorder, and the rapid return of patients to the community (Sederer & Dickey, 1995). Inpatient units are seen as short-term intensive settings to contain and resolve crises that cannot be resolved in the community. For this reason, inpatients are commonly suicidal, homicidal, or decompensating (experiencing the rapid return of severe symptoms) to the degree that they cannot care for themselves or respond to community-based services. Inpatient services therefore emphasize safety measures, crisis intervention, acute medication and re-evaluation of ongoing medications, and (re)establishing the client's links to other supports and services (Sederer & Dickey, 1997).

Mobile crisis services have developed in many urban areas to prevent hospitalization (Zealberg, 1997), as have day hospital programs. With crisis services, a multidisciplinary team comes directly to the aid of the client in the community to provide immediate evaluation and services. This new conceptualization of inpatient care and crisis intervention services minimizes the use of hospital resources; however, well-coordinated teams, sufficient community programs, and ready linkages are not widely available, particularly in rural and frontier areas.

African Americans and Native Americans are overrepresented in psychiatric inpatient units in relation to their representation in the population (Snowden & Cheung, 1990; Snowden, in press). Overrepresentation is found in hospitals of all types except private psychiatric hospitals. The reasons for this disparity, while not completely understood, may reflect a mix of limited access to outpatient services and differences in cultural patterns of help-seeking behavior and overt discriminatory practices. Cost, disinclination to seek help, and lack of community support may contribute to patients' delay in seeking treatment until symptoms are severe enough to warrant inpatient care. Clinician bias may also be at work. Cultural differences in treatment seeking and treatment utilization are discussed in greater detail in Chapter 2.

Services for Substance Abuse and Severe Mental Illness

As many as *half* of people with serious mental illnesses develop alcohol or other drug abuse problems at some point in their lives (Mueser et al., 1990; Regier et al., 1993, Drake & Osher, 1997). Theories to explain comorbidity (also known as dual diagnosis) range from genetic to psychosocial, but empirical support for any one theory is inconclusive (Kosten & Ziedonis, 1997; Mueser et al., 1998b). In short, the cause of such widespread comorbidity is unknown.

Comorbidity worsens clinical course and outcomes for individuals with mental disorders. It is associated with symptom exacerbation, treatment noncompliance, more frequent hospitalization, greater depression and likelihood of suicide, incarceration, family friction, and high services, use, and cost (Bartels et al., 1995; Mueser et al., 1997a; Bellack & Gearon, 1998; Havassy & Arns, 1998). Furthermore, patients may be jeopardized by the consequences of substance abuse, namely, increased risk of violence, HIV infection, and alcohol-related disorders (IOM, 1995).

In light of the extent of mental disorder and substance abuse comorbidity, substance abuse treatment is a critical element of treatment for people with mental disorders. Likewise, treatment of symptoms and signs of mental disorders is a critical element of recovery from substance abuse. Yet decades of treating comorbidity through separate mental health and substance abuse service systems proved ineffective (Ridgely et al., 1990; Mueser et al., 1997a).

Research amassed over the past 10 years supports a shift to treatment that combines interventions directed simultaneously to both conditions—that is, severe mental illness and substance abuse—by the same group of providers (Kosten & Ziedonis, 1997; for an example, see Mowbray et al. 1995), but access to such treatment remains limited. Most successful models of combined treatment include case management, group interventions (such as persuasion groups and social skills training), and assertive outreach to bring people into treatment (Mueser et al., 1997a). They typically take into account the cognitive and motivational deficits that characterize serious mental illnesses (Bellack & Gearon, 1998), although many providers still need to be educated (Kirchner et al., 1998). Combined treatment is effective at engaging people with both diagnoses in outpatient services, maintaining continuity and consistency of care, reducing hospitalization, and decreasing substance abuse, while at the same time improving social functioning (Miner et al., 1997; Mueser et al., 1997a).

Although there is little evidence for any particular approach to combining treatments for comorbidity (Ley et al., 1999), recent research suggests that services incorporating behavioral (motivational) approaches to substance abuse treatment are superior to traditional 12-step approaches (e.g., Alcoholics Anonymous) with this population of clients (Drake et al., 1998). This may be because the more structured behavioral methods better accommodate the cognitive difficulties that accompany schizophrenia. Others, however, find self-help interventions tailored to dual-diagnosis clients quite useful (Vogel et al., 1998). Current research also is seeking to tailor combined treatment to the needs and preferences of specific patient subgroups, such as men, women (Alexander, 1996), people with addiction to multiple substances (as opposed to alcohol addiction alone), and people with histories of physical and psychological trauma (Mueser et al., 1997a).

Other Services And Supports

Comprehensive care for adults with severe and persistent mental disorders also includes ancillary services to deal with such social consequences as family disruption and loss of employment and housing. Ancillary services are those above and beyond symptom management and rehabilitation. They include consumer self-help and advocacy, consumer-operated programs, family self-help and advocacy, and human services. The chapter concludes with a brief review of evidence about integrating the mental health service system and the human services system of which it is part.

A driving force for many of these services is to redress the stigma associated with severe and persistent mental illness. Stereotypes and ignorance are omnipresent (Robert Wood Johnson Foundation, 1990; Wahl et al., 1995). They lead many people to avoid living, socializing, or working with, renting to, or employing people with severe mental disorders (Levey et al., 1995). Stigma reduces consumers' access to resources and opportunities (e.g., housing, jobs), fuels isolation and hopelessness, and leads to outright discrimination and abuse. Thus, overcoming stigma represents yet another challenge of coping with severe and persistent mental illness and of working toward recovery (Wahl & Harman, 1989; Reidy, 1993).

Consumer Self-Help

Self-help groups are geared for mutual support, information, and growth. Self-help is based on the premise that people with a shared condition who come together can help themselves and each other to cope, with the two-way interaction of giving and receiving help considered advantageous. Self-help groups are peer led rather than professionally led.

Organized self-help has a long history, with an estimated 2 to 3 percent of the general population involved in some self-help group at any one time (Borkman, 1991, 1997). Over the past several decades, people with serious mental illnesses have formed mutual assistance organizations to aid each other and to combat stigma. These range from small groups held in a member's home to freestanding nonprofit organizations with paid staff and a range of programs. In general, however, the self-help empowerment trend does not appear to have reached the African-American, Native American, Hispanic/Latino, and Asian-American populations.

As the number and variety of self-help groups has grown, so too has social science research on their benefits (Borkman, 1991). In general, participation in self-help groups has been found to lessen feelings of isolation, increase practical knowledge, and sustain coping efforts (Powell, 1994; Kurtz, 1997). Similarly, for people with schizophrenia or other mental illnesses, participation in self-help groups increases knowledge and enhances coping (Borkman, 1997; Trainor et al., 1997). Various orientations include replacing self-defeating thoughts and actions with wellness-promoting activities (Murray, 1996), improved vocational involvement (Kaufmann, 1995), social support and shared problem solving (Mowbray & Tan, 1993), and crisis respite (Mead, 1997). Such orientations are thought to contribute greatly to increased coping, empowerment, and realistic hope for the future. Additionally, some groups are tailored to meet the needs of consumers who are members of sexual minority groups, men, or those who have also have substance disorders (Noordsy et al., 1996; Vogel et al., 1998).

A number of controlled studies have demonstrated benefits for consumers participating in self-help. One study of the self-help group Recovery, Inc., found that leaders and members who were surveyed retrospectively reported fewer symptoms and fewer hospitalizations after joining the group than before. It also found the leaders' reports of their psychological well-being to have been comparable to community controls (Galanter, 1988). In another study of 115 former mental patients, Luke (1989) found that those who continued to attend self-help meetings at least once per month over a period of 10 months were more likely to show improvement on psychological, interpersonal, or community adjustment measures than those who attended less frequently. Through a case study, which included focus groups and interviews, Lieberman and colleagues (1991) found a consumer-run support group to improve members' self-confidence and self-esteem and to lead to fewer hospitalizations.

In a survey of mental health self-help group leaders in New York State, respondents identified three positive outcomes that were directly related to their self-help group membership: greater self-esteem, more hopefulness about the future, and a greater sense of well-being. According to survey respondents, all of these positive changes led to fewer hospitalizations (Carpinello & Knight, 1993). A study of six self-help programs in several parts of the United States also reported on consumers' perceptions of self-help programs (Chamberlin & Rogers, 1990). Although not nationally representative, consumers in this study expressed satisfaction with their self-help program, at which they spent an average of 15 hours per week. They reported that their participation helped them to solve problems and feel more in control of their lives.

Consumer-Operated Programs

Propelled by the growing consumer movement, consumer self-help extends beyond self-help groups. It also encompasses consumer-operated programs, such as drop-in centers, case management programs, outreach programs, businesses, employment and housing programs, and crisis services, among others (Long & Van Tosh, 1988; National Resource Center on Homelessness and Mental Illness, 1989; Van Tosh & del Vecchio, in press). Drop-in centers are places for obtaining social support and assistance with problems, without professionals in attendance. The rationale for consumer roles in service delivery is that consumer staff, clients, and the mental health system can benefit. Consumer staff are thought to gain meaningful work, to serve as role models for clients, and to enhance the sensitivity of the service system to the needs of people with mental disorders. Clients are thought to gain from being served by staff who are more empathic and more capable of engaging them in mental health services (Mowbray et al., 1996).

An appreciation for the potential value of peer support stimulated the Community Support Program of the National Institute of Mental Health to fund local consumer-operated Services Demonstration Projects from 1988 to 1991. These demonstration projects also resulted in the increasing involvement of mental health consumers in the development and provision of peer support, involvement in traditional service roles, evaluation of services, and advocacy. A variety of consumer-operated programs were developed, staffed, and evaluated as states began to fund locally based initiatives (Nikkel et al., 1992; Kaufmann et al., 1993; Mowbray & Tan, 1993). Most evaluations of drop-in centers were in the form of process evaluations that generally found consumers to be satisfied or that programs met their objectives (Kaufmann et al., 1993; Mowbray & Tan, 1993). In 1998, the Federal Center for Mental Health Services initiated a multisite evaluation study of consumer-operated services across the United States (see *http://www.cstprogram.edu*).

In addition to ongoing evaluations, there are several published studies of client outcomes with consumer-run programs, although the research base is modest. Several studies, noted earlier, found improved outcomes with consumer self-help programs. Another study evaluated a consumer-run case management program. It compared the effectiveness of a case management program staffed by consumers with a similar program staffed by nonconsumers. Case managers in both programs, which were part of assertive community treatment, performed brokering, assistance, and support functions, rather than clinical management and treatment. The randomized trial found that clients assigned to either case management program fared equally well in clinical, social, and quality of life outcomes (Solomon & Draine, 1995). Recently, peer specialists were added to the recommended staffing for assertive community treatment teams; peer specialists provide expertise and consultation to the entire treatment team (Allness & Knoedler, 1999).

Consumers also may be employed as staff in more traditional mental health services operated by nonconsumer professionals. Consumer positions most commonly include peer counselors, peer job coaches, case managers, staff for drop-in centers, outreach workers, and housing assistants. In a survey of 400 agencies offering supported housing to people with severe mental illness, 38 percent employed mental health consumers as paid staff (Besio & Mahler, 1993). As noted previously, consumers in the role of peer-specialists integrated into case management teams led to improved patient outcomes (Felton et al., 1995).

Consumer Advocacy

The mental health field has witnessed great changes in policy development, with consumers playing increasingly visible roles in advocacy. Consumer contribution to policy was initially encouraged by Federal laws mandating consumer participation in planning, oversight, and advocacy activities at the state level (Chamberlin & Rogers, 1990; Van Tosh & del Vecchio, in press). With the establishment of state mental health planning councils and local mental health advisory boards and committees, consumers increasingly have become equal partners in a process often reserved for seasoned policymakers. In addition, consumers have become active participants in the process to reform health and mental health care financing. For example, the Managed Care Consortium was formed in 1995 to create educational opportunities for a host of advocacy organizations across the United States. With funding support from the federal Center for Mental Health Services, this consortium encouraged teams to form in each state to influence the design of managed care programs. Consumers also have entered the halls of many public sector bureaucracies, serving in leadership roles in Offices of Consumer Affairs and interfacing with other government departments. In what was once believed to be the last bastion for consumer integration, consumers are now seen as critical stakeholders and valued resources in the policy process.

Consumers also have become advocates in the communities where they live and work. Advocacy enables consumer groups to shape policy at the local level, where a direct impact can be felt. At the local level, advocacy strives to improve access to, or quality of, needed services and to counter employment and housing discrimination. It can also be helpful in mobilizing resources to build and sustain programs. The National Mental Health Association (NMHA, available at http://www.nmha.org), comprising more than 340 affiliates nationwide, works with and supports the efforts of consumers to achieve advocacy goals.

Family Self-Help

Family members of people with severe mental illnesses also encounter ignorance and stigma. Stigma translates into avoiding or blaming family members (Phelan et al., 1998; Wahl & Harman, 1989). Families also are under a great deal of stress associated with care giving and obtaining resources for their mentally ill members.

Families—especially parents, siblings, adult children, and spouses—often provide housing, food, transportation, encouragement, and practical assistance. At the same time, schizophrenia and other mental disorders strain family ties. Symptoms of mental disorders may be disruptive and troubling, especially when they flare up. Even when there are no problems, living together can be stressful—interpersonally, socially, and economically. Parents and their adult children often perceive mental disorders and treatment differently, sometimes disagreeing about the best course of action.

Consequently, families too have created support organizations. Some of these are professionally based and facilitated, often as part of a clinic or other treatment program. Others are peer run in the self-help model. Similar to self-help among people with mental illnesses, family self-help can range from small supportive groups to large organizations. The National Alliance for the Mentally Ill (NAMI) is the largest such organization. Founded in 1979 in Wisconsin, NAMI now has 208,000 members nationally. It has more than 1,200 local self-help groups (affiliates) across all 50 states (see *http://www.nami.org*). While still growing, its members include only a small percentage of the family members of people with mental illnesses in the country (Monking, 1994; Heller et al., 1997a).

Family members primarily attend self-help and support groups to receive emotional support and accurate information about mental illness and mental health services (Heller et al., 1997a, 1997b). Participation often leads to better quality of life for the attending family members and also indirectly benefits the member diagnosed as mentally ill (Wahl & Harman, 1989; Monking, 1994). Family self-help groups can result in better communication and interaction among family members (Heller et al., 1997b).

Family Advocacy

In addition to providing each other with mutual support, families often devote time, energy, and resources for advocacy to improve services and opportunities for their family members with mental disorders. Similar to consumer advocacy, family advocacy on a local level might include organizing to improve local mental health services, or to redress grievances with service providers. On the national level, consumer groups work to influence legislation and to support research and education initiatives (Wahl & Harman, 1989). Through their advocacy, families have been quite effective in raising their concerns and perspectives to service providers, legislators, and the public.

Human Services

The clinical symptoms of schizophrenia and other mental disorders are often disruptive and distressing. Their consequences are no less severe—truncated education, unemployment, social isolation, and exclusion from community participation. Facing multiple life stressors, all severe, with a minimum of resources, people with severe mental illnesses often need a variety of supportive services. Paramount among these are housing, employment and income assistance, and health benefits. Consumers have reported their major needs to include adequate income, meaningful employment, decent and affordable housing, quality health care, and education to increase skills (Ball & Havassy, 1984; Rosnow & Rucker, 1985; Lynch & Kruzich, 1986).

Housing

Housing ranks as a priority concern of individuals with serious mental illness. Locating affordable, decent, safe housing is often difficult, and out of financial reach. Stigma and discrimination also restrict consumer access to housing. Despite legislation such as the Fair Housing Act, allegations of housing discrimination based on psychiatric disabilities are highly prevalent (U.S. Department of Education, 1998). Landlords and public housing programs are often unwilling to accept tenants with severe mental disorders. In a survey of parents of mentally ill adults, the dearth of decent and affordable housing was a direct barrier to the person moving out of the family home, even when all parties wanted it (Hatfield, 1992).

The actual proportion of people with severe mental illnesses who lack affordable and decent housing has not been assessed directly. Yet indirect assessments point to a serious problem. In 1994, the U.S. Department of Housing and Urban Development (HUD) reported that almost half of all very low-income disabled residents—including persons with serious mental illness—have "worst case" needs for housing assistance. Furthermore, it was reported that the majority of these persons often live in the most severely inadequate housing (U.S. Department of Housing and Urban Development, 1994; U.S. Department of Education, 1998). It is estimated that up to one in three individuals who experience homelessness has a mental illness (Federal Interagency Task Force on Homelessness and Mental Illness, 1992).

The housing preferences of people with schizophrenia and other serious mental disorders are clear: these individuals strongly desire their own decent living quarters where they have control over who lives with them and how decisions are made (Owen et al., 1996; Schutt & Goldfinger, 1996; Sohng, 1996). In an analysis of 26 consumer preference surveys, Tanzman (1993) found that at least 59 percent of those surveyed wanted independent living in a house or apartment. They also preferred to live alone (or with a spouse or partner), yet not with other people with mental disorders. Most also preferred access to mental health and rehabilitation services to support them where they were living.

When deinstitutionalization led to the need for more community housing, the residential programs that were developed replicated institutional programs (Carling, 1989). Although residential programs varied in the degree of oversight and services, they generally proved to be ineffective in meeting consumers' needs. Moreover, living in such programs added to stigma. Because of these shortfalls, greater emphasis has been placed on conventional housing supplemented by appropriate assistance tailored to individual need (Srebnik et al., 1995). This new concept, called supported housing, moves away from "placing" clients, grouping clients by disability, staff monopolizing decisionmaking, and use of transitional settings and standardized levels of service (Carling, 1989; Lehman & Newman, 1996). Instead, supported housing focuses on consumers having a permanent home that is integrated socially, is self-chosen, and encourages empowerment and skills development. The services and supports offered are individualized, flexible, and responsive to changing consumer needs. Thus, instead of fitting a person into a housing program "slot," consumers choose their housing, where they receive support services. The level of support is expected to fluctuate over time. With residents living in conventional housing, some of the stigma attached to group homes and residential treatment programs is avoided.

Although there are no randomized clinical trials to support the effectiveness of the supported housing approach, consumer advocacy and changes in clinical practice affirm the shift to supported housing. In a quasi-experimental study, an evaluation of the Robert Wood Johnson Foundation Program on Chronic Mental Illness demonstrated the feasibility and modest benefits of the supported housing approach using rental subsidies from HUD (Newman et al., 1994). Consumers experienced better mental health and more self-determination when they lived in adequate housing (Nelson et al., 1998). For example, one study found that personal empowerment and functioning were enhanced, and hospitalization reduced, after 5 months in a supported housing program (McCarthy & Nelson, 1991). Also, resident control over decisions was directly related to satisfaction and empowerment (Seilheimer & Doyal, 1996). Similarly, another study found that having greater choice in housing was associated with greater happiness and life satisfaction (Srebnik et al., 1995).

Despite these findings, serious housing problems persist for people with schizophrenia and other mental disorders. Most such individuals are poor and thereby face very limited housing options.

Income, Education, and Employment

People with severe mental illnesses tend to be poor (Polak & Warner, 1996). Although the reasons are not understood, poverty is a risk factor for some mental disorders, as well as a predictor of poor long-term outcome among people already diagnosed (Cohen, 1993; Rabins et al., 1996; Saraceno & Barbui, 1997). People with serious mental illnesses often become dependent on public assistance shortly after their initial hospitalization (Ho et al., 1997). They rely on government disability-income programs, rent subsidies (Loyd & Tsuang, 1985; Polak & Warner, 1996; Ho et al., 1997), and informal sources of economic support (e.g., living with parents). The unemployment rate among adults with serious and persistent mental disorders hovers at 90 percent (National Institute on Disability and Rehabilitation Research, 1992).

Conversely, adequate standards of living and employment are associated with better clinical outcomes and quality of life (Cohen, 1993; Bell & Lysaker, 1997). In a randomized trial of consumers assigned to paid versus unpaid work, paid employment was found to reduce symptoms of schizophrenia (Bell et al., 1996). Moreover, employer accommodations for those with psychiatric disabilities appear to be inexpensive. The most frequently requested accommodations focus on orientation and training of supervisors, provision of onsite support, and adaptive work schedules. Such accommodations rarely result in significant cost to the employer (Mancuso, 1990; Fabian et al., 1993).

While newer vocational rehabilitation and employment initiatives strive to remedy persistently high levels of unemployment, most consumers find themselves unable to work consistently or at all. This is due not only to active symptoms but also to profound interruptions of education and employment caused by symptom onset and exacerbations, stigma and discrimination, lack of higher education programs for this population, and low-paying menial jobs.

When the onset of mental health problems begins during school-age years, educational systems are often ill prepared. Several studies have identified educational deficits in their clientele, who function in reading and math at a level far below their achieved grades in school (Cook et al., 1987; Cook & Solomon, 1993). Supported education models can provide assistance to consumers with their education (Cook & Solomon, 1993; Hoffman & Mastrianni, 1993; Ryglewicz & Glynn, 1993). One example is Consumers and Alliances United for Supported Education, a consumer-operated program in Quincy, Massachusetts, that provides a wide range of services to encourage individuals with psychiatric disabilities to enter or reenter college or technical school programs. Services include academic and career counseling, assistance with finding financial aid, study skills, stress control, tutoring/coaching, and assistance with crisis while hospitalized (CMHS, 1996).

Consumers lack control over their financial affairs when benefit checks are given directly to care providers for the person's housing and other expenses, or to a legally appointed representative payee (if the person has been deemed unable to manage his/her own finances) (Conrad et al., 1998). Those consumers who manage their own finances usually face such modest monthly budgets that there is no room for error. Funds frequently are depleted before the end of the month. Furthermore, disability payments are sometimes reduced or discontinued when a recipient is working. Since employment is rarely consistent, they need to resume disability benefits. Yet, once they are canceled, government disability benefits can be cumbersome to restart. The Social Security Administration has developed new measures to facilitate reactivation of benefits for individuals who return to work, but they are not yet widely disseminated. In some ways the requirements of Social Security disability benefits and other such programs often act as disincentives to the pursuit of employment (Polak & Warner, 1996; Priebe et al., 1998).

Some people with serious mental illnesses have adequate income or financial assistance (Ware & Goldfinger, 1997). Some have affluent families who can subsidize their expenses. Others collect pensions because they were not disabled by their illness until after they had a substantial work history. Finally, some have found well-paying positions through a formal rehabilitation program, a community-based educational or vocational training program, or a supportive employer.

Health Coverage

Health coverage goes hand in hand with housing and income in determining standards of living for people with serious psychiatric disabilities. Due to their low incomes and the high cost of psychiatric and other health services, most people with schizophrenia and other forms of severe and persistent mental disorders rely on Medicare, Medicaid, and other government programs to cover their therapeutic services, medications, and other health care. When reductions or loss of these benefits curtail access to needed medication or services, clients' health suffers and their use of more expensive emergency services increases (Soumerai et al., 1994). Even when they have access to health insurance coverage, individuals with a mental disorder encounter barriers to procuring that insurance and in receiving general medical care (Druss & Rosenheck 1998).

Integrating Service Systems

Integrating the range of services needed by individuals with severe and persistent mental disorders has been a vexing problem for decades. The General Accounting Office (1977) criticized the Federal community mental health centers for their failure to meet the multiple needs of individuals with chronic mental illness. The Federal response was to establish a Community Support Program to provide resources and technical assistance to communities to help them in formulating community support systems to integrate the various services provided by fragmented human services agencies (Turner & TenHoor, 1978; Tessler & Goldman, 1982). The limitations of a community support program in dealing with severe and persistent mental illness in major cities, particularly those with high rates of homelessness, prompted the Robert Wood Johnson Foundation to partner with HUD to create the Program on Chronic Mental Illness (Aiken et al., 1986). This program promoted the concept of local mental health authorities as the agencies responsible for integrating all services for individuals with chronic mental illness, including housing opportunities (Shore & Cohen, 1990, 1994). The Robert Wood Johnson Foundation Program on Chronic Mental Illness was initiated in late 1986 and evaluated over a 6-year period (Goldman et al., 1990a, 1990b, 1994a, 1994b).

The evaluation determined that local mental health authorities were established or strengthened in almost all of the nine cities, resulting in measurable increases in organizational centralization and reduced fragmentation of services (Morrissey et al., 1994). Case management services also were expanded, producing greater continuity of care and reductions in family burden (Lehman et al., 1994; Shern et al., 1994; Tessler et al., 1994). Client outcomes, including social functioning and quality of life measures, improved during the demonstration (Lehman et al., 1994; Shern et al., 1994). Yet the time course of most clients' improvement did not coincide with improvements in system integration. This suggested that their improvement could not be attributed to system integration. For a subset of clients, improved client outcomes were due to the benefits of special combined housing and support services. Yet, even for this subset, improvements were related, but not directly attributable, to systems integration (Newman et al., 1994).

Evaluators concluded that system integration and traditional case management alone probably were not sufficient to produce optimal social and clinical outcomes (Goldman et al., 1994b; Lehman et al., 1994). They speculated that the availability of rental subsidies and supports or more intensive and higher quality case management services—such as those offered in assertive community treatment—were essential (Ridgely et al., 1996). This set of findings, coincident with the release of the report of the Federal Interagency Task Force on Homelessness and Mental Illness (1992), *Outcasts on Main Street*, prompted the development of another demonstration program.

Access to Community Care and Effective Services and Supports was launched by the Federal Center for Mental Health Services in 1993 (Randolph et al., 1997). Still in the midst of its evaluation, preliminary findings sustain the benefits of providing assertive community treatment to obtain good clinical and social outcomes. They support the association of better system integration with higher rates of moving individuals with severe mental illness from homelessness into independent housing (Rosenheck et al., 1998a). It remains to be seen, however, whether the improvements in system integration observed over time are associated with improvements in consumers' clinical and social outcomes.

Integrating service systems remains a challenge to mental health and related human service agencies. Its benefits for accountability and centralization of authority have been established. Its impact on individuals with severe and persistent mental illness may be limited by the lack of available high-quality services and mainstream welfare resources, reflecting the gap between what can be done and what is available (Goldman, 1998a).

Conclusions

1. As individuals move into adulthood, developmental goals focus on productivity and intimacy including pursuit of education, work, leisure, creativity, and personal relationships. Good mental health enables individuals to cope with adversity while pursuing these goals.
2. Untreated, mental disorders can lead to lost productivity, unsuccessful relationships, and significant distress and dysfunction. Mental illness in adults can have a significant and continuing effect on children in their care.
3. Stressful life events or the manifestation of mental illness can disrupt the balance adults seek in life and result in distress and dysfunction. Severe or life-threatening trauma experienced either in childhood or adulthood can further provoke emotional and behavioral reactions that jeopardize mental health.
4. Research has improved our understanding of mental disorders in the adult stage of the life cycle. Anxiety, depression, and schizophrenia, particularly, present special problems in this age group. Anxiety and depression contribute to the high rates of suicide in this population. Schizophrenia is the most persistently disabling condition, especially for young adults, in spite of recovery of function by some individuals in mid to late life.
5. Research has contributed to our ability to recognize, diagnose, and treat each of these conditions effectively in terms of symptom control and behavior management. Medication and other therapies can be independent, combined, or sequenced depending on the individual's diagnosis and personal preference.
6. A new recovery perspective is supported by evidence on rehabilitation and treatment as well as by the personal experiences of consumers.
7. Certain common events of midlife (e.g., divorce or other stressful life events) create mental health problems (not necessarily disorders) that may be addressed through a range of interventions.
8. Care and treatment in the real world of practice do not conform to what research determines as best. For many reasons, at times care is inadequate but there are models for improving treatment.
9. Substance abuse is a major co-occurring problem for adults with mental disorders. Evidence supports combined treatment, although there are substantial gaps between what research recommends and what typically is available in communities.
10. Several special problems in care and treatment of adults have been recognized, beyond traditional mainstream mental health concerns, including racial and ethnic differences, lack of consumer involvement, and the consequences of disability and poverty.
11. Barriers of access exist in the organization and financing of services for adults. There are specific problems with Medicare, Medicaid, income supports, housing, and managed care.

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CHAPTER 5

OLDER ADULTS AND MENTAL HEALTH

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CHAPTER 5

OLDER ADULTS AND MENTAL HEALTH

The past century has witnessed a remarkable lengthening of the average life span in the United States, from 47 years in 1900 to more than 75 years in the mid-1990s (National Center for Health Statistics [NCHS], 1993). Equally noteworthy has been the increase in the number of persons ages 85 and older (Figure 5-1). These trends will continue well into the next century and be magnified as the numbers of older Americans increase with the aging of the post–World War II baby boom generation.

Millions of older Americans—indeed, the majority—cope constructively with the physical limitations, cognitive changes, and various losses, such as bereavement, that frequently are associated with late life. Research has contributed immensely to our understanding of developmental processes that continue to unfold as we age. Drawing on new scientific information and acting on clinical common sense, mental health and general health care providers are increasingly able to suggest mental health strategies and skills that older adults can hone to make this stage of the life span satisfying and rewarding.

The capacity for sound mental health among older adults notwithstanding, a substantial proportion of the population 55 and older—almost 20 percent of this age group—experience specific mental disorders that are not part of "normal" aging (see Table 5-1). Research that has helped differentiate mental disorders from "normal" aging has been one of the more important achievements of recent decades in the field of geriatric health. Unrecognized or untreated, however, depression, Alzheimer's disease, alcohol and drug misuse and abuse, anxiety, late-life schizophrenia, and other conditions can be severely impairing, even fatal:

Figure 5-1. Increases in the percent of the U.S. population over age 65 years and over age 85 years (Malmgren, 1994).

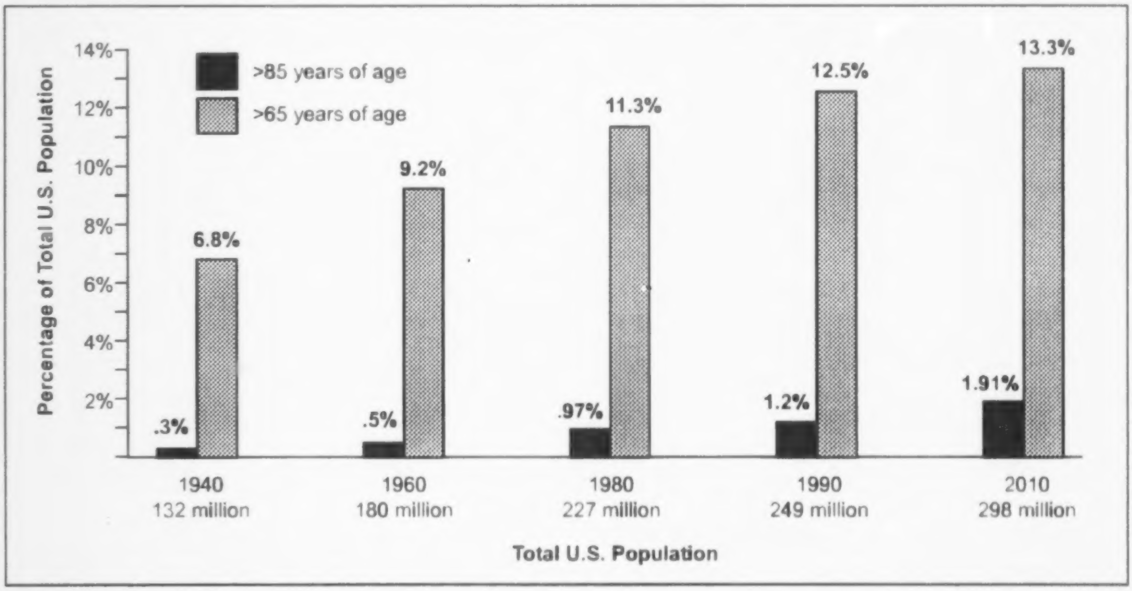

Table 5-1. Best Estimate 1-Year Prevalence Rates Based on Epidemiologic Catchment Area, Age 55+

	Prevalence (%)
Any Anxiety Disorder	11.4
Simple Phobia	7.3
Social Phobia	1.0
Agoraphobia	4.1
Panic Disorder	0.5
Obsessive-Compulsive Disorder	1.5
Any Mood Disorder	4.4
Major Depressive Episode	3.8
Unipolar Major Depression	3.7
Dysthymia	1.6
Bipolar I	0.2
Bipolar II	0.1
Schizophrenia	0.6
Somatization	0.3
Antisocial Personality Disorder	0.0
Anorexia Nervosa	0.0
Severe Cognitive Impairment	6.6
Any Disorder	19.8

Source: D. Regier & W. Narrow, personal communication, 1999.

in the United States, the rate of suicide, which is frequently a consequence of depression, is highest among older adults relative to all other age groups (Hoyert et al., 1999). The clinical challenges such conditions present may be exacerbated, moreover, by the manner in which they both affect and are affected by general medical conditions or by changes in cognitive capacities. Another complicating factor is that many older people, disabled by or at risk for mental disorders, find it difficult to afford and obtain needed medical and related health care services. Late-life mental disorders also can pose difficulties for the burgeoning numbers of family members who assist in caretaking tasks for their loved ones (Light & Lebowitz, 1991).

Chapter Overview

Fortunately, the past 15 to 20 years have been marked by rapid growth in the number of clinical, research, and training centers dedicated to the mental illness- and mental health-related needs of older people. As evident in this chapter, much has been learned. The chapter reviews, first, normal developmental milestones of aging, highlighting the adaptive capacities that enable many older people to change, cope with loss, and pursue productive and fulfilling activities. The chapter then considers mental disorders in older people—their diagnosis and treatment, and the various risk factors that may complicate the course or outcome of treatment. Risk factors include co-occurring, or comorbid, general medical conditions, the high numbers of medications many older individuals take, and psychosocial stressors such as bereavement or isolation. These are cause for concern, but, as the chapter notes, they also point the way to possible new preventive interventions. The goal of such prevention strategies may be to limit disability or to postpone or even eliminate the need to institutionalize an ill person (Lebowitz & Pearson, in press). The chapter reviews gains that have been realized in making appropriate mental health services available to older people and the challenges associated with the delivery of services to this population. The advantages of a decisive shift away from mental hospitals and nursing homes to treatment in community-based settings today are in jeopardy of being undermined by fragmentation and insufficient availability of such services (Gatz & Smyer, 1992; Cohen & Cairl, 1996). The chapter examines obstacles and opportunities in the service delivery sphere, in part through the lens of public and private sector financing policies and managed care.

Finally, the chapter reviews the supports for older persons that extend beyond traditional, formal treatment settings. Through support networks, self-help groups, and other means, consumers, families, and communities are assuming an increasingly important

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role in treating and preventing mental health problems and disorders among older persons.

Normal Life-Cycle Tasks

With improved diet, physical fitness, public health, and health care, more adults are reaching age 65 in better physical and mental health than in the past. Trends show that the prevalence of *chronic* disability among older people is declining: from 1982 to 1994, the prevalence of chronic disability diminished significantly, from 24.9 to 21.3 percent of the older population (Manton et al., 1997). While some disability is the result of more general losses of physiological functions with aging (i.e., normal aging), *extreme* disability in older persons, including that which stems from mental disorders, is not an inevitable part of aging (Cohen, 1988; Rowe & Kahn, 1997).

Normal aging is a gradual process that ushers in some physical decline, such as decreased sensory abilities (e.g., vision and hearing) and decreased pulmonary and immune function (Miller, 1996; Carman, 1997). With aging come certain changes in mental functioning, but very few of these changes match commonly held negative stereotypes about aging (Cohen, 1988; Rowe & Kahn, 1997). In normal aging, important aspects of mental health include stable intellectual functioning, capacity for change, and productive engagement with life.

Cognitive Capacity With Aging

Cognition subsumes intelligence, language, learning, and memory. With advancing years, cognitive capacity with aging undergoes some loss, yet important functions are spared. Moreover, there is much variability between individuals, variability that is dependent upon lifestyle and psychosocial factors (Gottlieb, 1995). Most important, accumulating evidence from human and animal research finds that lifestyle modifies genetic risk in influencing the outcomes of aging (Finch & Tanzi, 1997). This line of research is beginning to dispel the pejorative stereotypes of older people as rigidly shaped by heredity and incapable of broadening their pursuits and acquiring new skills.

A large body of research, including both cross-sectional studies and longitudinal studies, has investigated changes in cognitive function with aging. Studies have found that working memory declines with aging, as does long-term memory (Siegler et al., 1996), with decrements more apparent in recall than in recognition capacities. Slowing or some loss of other cognitive functions takes place, most notably in information processing, selective attention, and problem-solving ability, yet findings are variable (Siegler et al., 1996). These cognitive changes translate into a slower pace of learning and greater need for repetition of new information. Vocabulary increases slightly until the mid-70s, after which it declines (Carman, 1997). In older people whose IQ declines, somatic illness is implicated in some cases (Cohen, 1988). Fluid intelligence, a form of intelligence defined as the ability to solve novel problems, declines over time, yet research finds that fluid intelligence can be enhanced through training in cognitive skills and problem-solving strategies (Baltes et al., 1989).

Memory complaints are exceedingly common in older people, with 50 to 80 percent reporting subjective memory complaints (cited in Levy-Cushman & Abeles, in press). However, subjective memory complaints do not correspond with actual performance. In fact, some who complain about memory display performance superior to those who do not complain (Collins & Abeles, 1996). Memory complaints in older people, according to several studies, are thought to be more a product of depression than of decline in memory performance (cited in Levy-Cushman & Abeles, in press). (The importance of proper diagnosis and treatment of depression is emphasized in subsequent sections of this chapter.) Studies attempting to treat memory complaints associated with normal aging—using either pharmacological or psychosocial means—have been, with few exceptions, unsuccessful (Crook, 1993). In one of these exceptions, a recent study demonstrated a significant reduction in memory complaints with training workshops for healthy older people. The workshops stressed not only memory promotion strategies, but also ways of dealing with expectations and perceptions about memory loss (Levy-Cushman & Abeles, in press).

One large, ongoing longitudinal study found high cognitive performance to be dependent on four factors, ranked here in decreasing order of importance: education, strenuous activity in the home, peak pulmonary flow rate, and "self-efficacy," which is a personality measure defined by the ability to organize and execute actions required to deal with situations likely to happen in the future (Albert et al., 1995). Education, as assessed by years of schooling, is the strongest predictor of high cognitive functioning. This finding suggests that education not only has salutary effects on brain function earlier in life, but also foreshadows sustained productive behavior in later life, such as reading and performing crossword puzzles (Rowe & Kahn, 1997).

The coexistence of mental and somatic disorders (i.e., comorbidity) is common (Kramer et al., 1992). Some disorders with primarily somatic symptoms can cause cognitive, emotional, and behavioral symptoms as well, some of which rise to the level of mental disorders. At that point, the mental disorder may result from an effect of the underlying disorder on the central nervous system (e.g., dementia due to a medical condition such as hypothyroidism) or an effect of treatment (e.g., delirium due to a prescribed medication). Likewise, mental problems or disorders can lead to or exacerbate other physical conditions by decreasing the ability of older adults to care for themselves, by impairing their capacity to rally social support, or by impairing physiological functions. For example, stress increases the risk of coronary heart disease and can suppress cellular immunity (McEwen, 1998). Depression can lead to increased mortality from heart disease and possibly cancer (Frasure-Smith et al., 1993, 1995; Penninx et al., 1998).

A new model postulates that successful aging is contingent upon three elements: avoiding disease and disability, sustaining high cognitive and physical function, and engaging with life (Rowe & Kahn, 1997). The latter encompasses the maintenance of interpersonal relationships and productive activities, as defined by paid or unpaid activities that generate goods or services of economic value. The three major elements are considered to act in concert, for none is deemed sufficient by itself for successful aging. This new model broadens the reach of health promotion in aging to entail more than just disease prevention.

Change, Human Potential, and Creativity

Descriptive research reveals evidence of the capacity for constructive change in later life (Cohen, 1988). The capacity to change can occur even in the face of mental illness, adversity, and chronic mental health problems. Older persons display flexibility in behavior and attitudes and the ability to grow intellectually and emotionally. Time plays a key role. Externally imposed demands upon one's time may diminish, and the amount of time left at this stage in life can be significant. In the United States in the late 20th century, late-life expectancy approaches another 20 years at the age of 65. In other words, average longevity from age 65 today approaches what had been the average longevity from birth some 2,000 years ago. This leaves plenty of time to embark upon new social, psychological, educational, and recreational pathways, as long as the individual retains good health and material resources.

In his classic developmental model, Erik Erikson characterized the final stage of human development as a tension between "ego integrity and despair" (Erikson, 1950). Erikson saw the period beginning at age 65 years as highly variable. Ideally, individuals at this stage witness the flowering of seeds planted earlier in the prior seven stages of development. When they achieve a sense of integrity in life, they garner pride from their children, students and protégés, and past accomplishments. With contentment comes a greater tolerance and acceptance of the decline that naturally accompanies the aging process. Failure to achieve a satisfying degree of ego integrity can be accompanied by despair.

Cohen (in press) has proposed that with increased longevity and health, particularly for people with adequate resources, aging is characterized by two human potential phases. These phases, which emphasize the positive aspects of the final stages of the life cycle, are termed *Retirement/Liberation* and *Summing Up/Swan Song*.

Retirement often is viewed as the most important life event prior to death. Retirement frequently is associated with negative myths and stereotypes (Sheldon et al., 1975; Bass, 1995). Cohen points out, however, that most people fare well in retirement. They have the opportunity to explore new interests, activities, and relationships due to retirement's liberating qualities. In the Retirement/Liberation phase, new feelings of freedom, courage, and confidence are experienced. Those at risk for faring poorly are individuals who typically do not want to retire, who are compelled to retire because of poor health, or who experience a significant decline in their standard of living (Cohen, 1988). In short, the liberating experience of having more time and an increased sense of freedom can be the springboard for creativity in later life. Creative achievement by older people can change the course of an individual, family, community, or culture.

In the late-life Summing Up/Swan Song phase, there is a tendency to appraise one's life work, ideas, and discoveries and to share them with family or society. The desire to sum up late in life is driven by varied feelings, such as the desire to complete one's life work, the desire to give back after receiving much in life, or the fear of time evaporating. Important opportunities for creative sharing and expression ensue. There is a natural tendency with aging to reminisce and elaborate stories that has propelled the development of reminiscence therapy for health promotion and disease prevention. The swan song, the final part of this phase, connotes the last act or final creative work of a person before retirement or death.

There is much misunderstanding about thoughts of death in later life. Depression, serious loss, and terminal illness trigger the sense of mortality, regardless of age. Contrary to popular stereotypes, studies on aging reveal that most older people generally do not have a fear or dread of death in the absence of being depressed, encountering serious loss, or having been recently diagnosed with a terminal illness (Kastenbaum, 1985). Periodic thoughts of death—not in the form of dread or angst—do occur. But these are usually associated with the death of a friend or family member. When actual dread of death does occur, it should not be dismissed as accompanying aging, but rather as a signal of underlying distress (e.g., depression). This is particularly important in light of the high risk of suicide among depressed older adults, which is discussed later in this chapter.

Coping With Loss and Bereavement

Many older adults experience loss with aging—loss of social status and self-esteem, loss of physical capacities, and death of friends and loved ones. But in the face of loss, many older people have the capacity to develop new adaptive strategies, even creative expression (Cohen, 1988, 1990). Those experiencing loss may be able to move in a positive direction, either on their own, with the benefit of informal support from family and friends, or with formal support from mental health professionals.

The life and work of William Carlos Williams are illustrative. Williams was a great poet as well as a respected physician. In his 60s, he suffered a stroke that prevented him from practicing medicine. The stroke did not affect his intellectual abilities, but he became so severely depressed that he needed psychiatric hospitalization. Nonetheless, Williams, with the help of treatment for a year, surmounted the depression and for the next 10 years wrote luminous poetry, including the Pulitzer Prize-winning *Pictures From Bruegel*, which was published when he was 79. In his later life, Williams wrote about "old age that adds as it takes away." What Williams and his poetry epitomize is that age can be the catalyst for tapping into creative potential (Cohen, 1998a).

Loss of a spouse is common in late life. About 800,000 older Americans are widowed each year. Bereavement is a natural response to death of a loved one. Its features, almost universally recognized, include crying and sorrow, anxiety and agitation, insomnia, and loss of appetite (Institute of Medicine [IOM], 1984). This constellation of symptoms, while overlapping somewhat with major depression, does not by itself constitute a mental disorder. Only when symptoms persist for 2 months and longer after the loss does the

DSM-IV permit a diagnosis of either adjustment disorder or major depressive disorder. Even though bereavement of less than 2 months' duration is not considered a mental disorder, it still warrants clinical attention (DSM-IV). The justification for clinical attention is that bereavement, as a highly stressful event, increases the probability of, and may cause or exacerbate, mental *and* somatic disorders.

Bereavement is an important and well-established risk factor for depression. At least 10 to 20 percent of widows and widowers develop clinically significant depression during the first year of bereavement. Without treatment, such depressions tend to persist, become chronic, and lead to further disability and impairments in general health, including alterations in endocrine and immune function (Zisook & Shuchter, 1993; Zisook et al., 1994). Several preventive interventions, including participation in self-help groups, have been shown to prevent depression among widows and widowers, although one study suggested that self-help groups can exacerbate depressive symptoms in certain individuals (Levy et al., 1993). These are described later in this chapter.

Bereavement-associated depression often coexists with another type of emotional distress, which has been termed traumatic grief (Prigerson et al., in press). The symptoms of traumatic grief, although not formalized as a mental disorder in DSM-IV, appear to be a mixture of symptoms of both pathological grief and post-traumatic stress disorder (Frank et al., 1997a). Such symptoms are extremely disabling, associated with functional and health impairment and with persistent suicidal thoughts, and may well respond to pharmacotherapy (Zygmont et al., 1998). Increased illness and mortality from suicide are the most serious consequences of late-life depression.

The dynamics around loss in later life need greater clarification. One pivotal question is why some, in confronting loss with aging, succumb to depression and suicide—which, as noted earlier, has its highest frequency after age 65—while others respond with new adaptive strategies. Research on health promotion also needs to identify ways to prevent adverse reactions and to promote positive responses to loss in later life. Meanwhile, despite cultural attitudes that older persons can handle bereavement by themselves or with support from family and friends, it is imperative that those who are unable to cope be encouraged to access mental health services. Bereavement is not a mental disorder but, if unattended to, has serious mental health and other health consequences.

Overview of Mental Disorders in Older Adults

Older adults are encumbered by many of the same mental disorders as are other adults; however, the prevalence, nature, and course of each disorder may be very different. This section provides a general overview of assessment, diagnosis, and treatment of mental disorders in older people. Its purpose is to describe issues common to many mental disorders. Subsequent sections of this chapter provide more detailed reviews of late-life depression and Alzheimer's disease. Also, to shed light on the range and frequency of disorders that impair the mental well-being of older Americans, the chapter reviews the impact on older adults of anxiety, schizophrenia, and alcohol and substance abuse.

Assessment and Diagnosis

Assessment and diagnosis of late-life mental disorders are especially challenging by virtue of several distinctive characteristics of older adults. First, the clinical presentation of older adults with mental disorders may be different from that of other adults, making detection of treatable illness more difficult. For example, many older individuals present with somatic complaints and experience symptoms of depression and anxiety that do not meet the full criteria for depressive or anxiety disorders. The consequences of these subsyndromal conditions may be just as deleterious as the syndromes themselves. Failure to detect individuals who truly have treatable mental disorders represents a serious public health problem (National Institutes of Health [NIH] Consensus Development Panel on Depression in Late Life, 1992).

Detection of mental disorders in older adults is complicated further by high comorbidity with other medical disorders. The symptoms of somatic disorders may mimic or mask psychopathology, making diagnosis more taxing. In addition, older individuals are more likely to report somatic symptoms than psychological ones, leading to further underidentification of mental disorders (Blazer, 1996b).

Primary care providers carry much of the burden for diagnosis of mental disorders in older adults, and, unfortunately, the rates at which they recognize and properly identify disorders often are low. With respect to depression, for example, a significant number of depressed older adults are neither diagnosed nor treated in primary care (NIH Consensus Development Panel on Depression in Late Life, 1992; Unutzer et al., 1997b). In one study of primary care physicians, only 55 percent of internists felt confident in diagnosing depression, and even fewer (35 percent of the total) felt confident in prescribing antidepressants to older persons (Callahan et al., 1992). Physicians were *least* likely to report that they felt "very confident" in evaluating depression in other late-life conditions (Gallo et al., in press). Researchers estimate that an *unmet* need for mental health services may be experienced by up to 63 percent of adults aged 65 years and older with a mental disorder, based on prevalence estimates from the Epidemiologic Catchment Area (ECA) study (Rabins, 1996).

The large unmet need for treatment of mental disorders reflects *patient* barriers (e.g., preference for primary care, tendency to emphasize somatic problems, reluctance to disclose psychological symptoms), *provider* barriers (e.g., lack of awareness of the manifestations of mental disorders, complexity of treatment, and reluctance to inform patients of a diagnosis), and mental health delivery *system* barriers (e.g., time pressures, reimbursement policies).

Stereotypes about normal aging also can make diagnosis and assessment of mental disorders in late life challenging. For example, many people believe that "senility" is normal and therefore may delay seeking care for relatives with dementing illnesses. Similarly, patients and their families may believe that depression and hopelessness are natural conditions of older age, especially with prolonged bereavement.

Cognitive decline, both normal and pathological, can be a barrier to effective identification and assessment of mental illness in late life. Obtaining an accurate history, which may need to be taken from family members, is important for diagnosis of most disorders and especially for distinguishing between somatic and mental disorders. Normal decline in short-term memory and especially the severe impairments in memory seen in dementing illnesses hamper attempts to obtain good patient histories. Similarly, cognitive deficits are prominent features of many disorders of late life that make diagnosis of psychiatric disorders more difficult.

Overview of Prevention

Prevention in mental health has been seen until recently as an area limited to childhood and adolescence. Now there is mounting awareness of the value of prevention in the older population. While the body of published literature is not as extensive as that for diagnosis or treatment, investigators are beginning to shape new approaches to prevention. Yet because prevention research is driven, in part, by refined understanding of disease etiology—and etiology research itself continues to be rife with uncertainty—prevention advances are expected to lag behind those in etiology.

There are many ways in which prevention models can be applied to older individuals, provided a broad view of prevention is used (Lebowitz & Pearson, in press). Such a broad view entails interventions for reducing the risk of developing, exacerbating, or experiencing the consequences of a mental disorder. Consequently, this section covers primary prevention (including the prevention of depression and suicide), treatment-related prevention, prevention of excess disability, and prevention of premature institutionalization. However, many of the research advances noted in this section have yet to be translated into practice. Given the frequency of memory complaints and depression, the time may soon arrive for older adults to be encouraged to have "mood and memory checkups" in the same manner that they are now encouraged to have physical checkups (N. Abeles, personal communication, 1998).

Primary Prevention

Primary prevention, the prevention of disease before it occurs, can be applied to late-onset disorders. Progress in our understanding of etiology, risk factors, pathogenesis, and the course of mental disorders—discussed later in this chapter for depression, Alzheimer's disease, and other conditions—stimulates and channels the development of prevention interventions.

The largest body of primary prevention research focuses on late-life depression, where some progress has been documented. With other disorders, primary prevention research is in its infancy. Prevention in Alzheimer's disease might target individuals at increased genetic risk with prophylactic nutritional (e.g., vitamin E), cholinergic, or amyloid-targeting interventions. Prevention research on late-onset schizophrenia might explore potential protective factors, such as estrogen.

Prevention of Depression and Suicide

Depression is strikingly prevalent among older people. As noted below, 8 to 20 percent of older adults in the community and up to 37 percent in primary care settings experience symptoms of depression.

One approach to preventing depression is through grief counseling for widows and widowers. For example, participation in self-help groups appears to ameliorate depression, improve social adjustment, and reduce the use of alcohol and other drugs of abuse in widows (Constantino, 1988; Lieberman & Videka-Sherman, 1986). The efficacy of self-help groups approximates that of brief psychodynamic psychotherapy in older bereaved individuals without significant prior psychopathology (Marmar et al., 1988). The battery of psychosocial and pharmacological treatments to prevent *recurrences* of depression (i.e., secondary prevention) is discussed later in this chapter under the section on depression.

Depression is a foremost risk factor for suicide in older adults (Conwell, 1996; Conwell et al., 1996). Older people have the highest rates of suicide in the U.S. population: suicide rates increase with age, with older white men having a rate of suicide up to six times that of the general population (Kachur et al., 1995; Hoyert et al., 1999). Despite the prevalence of depression and the risk it confers for suicide, depression is neither well recognized nor treated in primary care settings, where most older adults seek and receive health care (Unutzer et al., 1997a). Studies described in the depression section of this chapter have found that undiagnosed and untreated depression in the primary care setting plays a significant role in suicide (Caine et al., 1996). This awareness has prompted the development of suicide prevention strategies expressly for primary care. One of the first published suicide prevention studies, an uncontrolled experiment conducted in Sweden, suggested that a depression training program for general practitioners reduces suicide (Rihmer et al., 1995). Suicide interventions, especially in the primary care setting, have become a priority of the U.S. Public Health Service, with lead responsibility assumed by the Office of the Surgeon General and the National Institute of Mental Health.

Depression and suicide prevention strategies also are important for nursing home residents. About half of patients newly relocated to nursing homes are at heightened risk for depression (Parmelee et al., 1989).

Treatment-Related Prevention

Prevention of relapse or recurrence of the underlying mental disorder is important for improving the mental health of older patients with mental disorders. For example, treatments that are applied with adequate intensities for depression (Schneider, 1996) and for depression in Alzheimer's disease (Small et al., 1997) may prevent relapse or recurrence. Substantial residual disability in chronically mentally ill individuals (Lebowitz et al., 1997) suggests that treatment must be approached from a longer term perspective (Reynolds et al., 1996).

Prevention of medication side effects and adverse reactions also is an important goal of treatment-related prevention efforts in older adults. Comorbidity and the associated polypharmacy for multiple conditions are characteristic of older patients. New information on the genetic basis of drug metabolism and on the action of drug-metabolizing enzymes can lead to a better understanding of complex drug interactions (Nemeroff et al., 1996). For example, many of the selective serotonin reuptake inhibitors compete for the same metabolic pathway used by beta-blockers, type 1C anti-arrhythmics, and benzodiazepines (Nemeroff et al., 1996). This knowledge can assist the clinician in choosing medications that can prevent the likelihood of side effects. In addition, many older patients require antipsychotic treatment for management of behavioral symptoms in Alzheimer's disease, schizophrenia, and depression. Although doses tend to be quite low, age and length of treatment represent major risk factors for movement disorders (Saltz et al., 1991; Jeste et al., 1995a). Recent research on older people suggests that the newer antipsychotics present a much lower risk of movement disorders, highlighting their importance for prevention (Jeste et al., in press). Finally, body sway and postural stability are affected by many drugs, although there is wide variability within classes of drugs (Laghrissi-Thode et al., 1995). Minimizing the risk of falling, therefore, is another target for prevention research. Falls represent a leading cause of injury deaths among older persons (IOM, 1999).

Prevention of Excess Disability

Prevention efforts in older mentally ill populations also target avoidance of excessive disability. The concept of excess disability refers to the observation that many older patients, particularly those with Alzheimer's disease and other severe and persistent mental disorders, are more functionally impaired than would be expected according to the stage or severity of their disorder. Medical, psychosocial, and environmental factors all contribute to excess disability. For example, depression contributes to excess disability by hastening functional impairment in patients with Alzheimer's disease (Ritchie et al., 1998). The fast pace of modern life, with its emphasis on independence, also contributes to excess disability by making it more difficult for older adults with impairments to function autonomously. Attention to depression, anxiety, and other mental disorders may reduce the functional limitations associated with concomitant mental and somatic impairments. Many studies have demonstrated that attention to these factors and aggressive intervention, where appropriate, maximize function (Lebowitz & Pearson, in press).

Prevention of Premature Institutionalization

Another important goal of prevention efforts in older adults is prevention of premature institutionalization. While institutional care is needed for many older patients who suffer from severe and persistent mental disorders, delay of institutional placement until absolutely necessary generally is what patients and family caregivers prefer. It also has significant public health impact in terms of reducing costs. A randomized study of counseling and support versus usual care for family caregivers of patients with Alzheimer's disease found the intervention to have delayed patients' nursing home admission by over 300 days (Mittelman et al., 1996). The intervention also resulted in a significant reduction in depressive symptoms in the caregivers. The intervention consisted of three elements: individual and family counseling sessions, support group participation, and availability of counselors to assist with patient crises.

The growing importance of avoiding premature institutionalization is illustrated by its use as one measure of the effectiveness of pharmacotherapy in older individuals. For example, clinical trials of drugs for Alzheimer's disease have begun using delay of institutionalization as a primary outcome (Sano et al., 1997) or as a longer-term outcome in a followup study after the double-blind portion of the clinical trial ended (Knopman et al., 1996).

Overview of Treatment

Treatment of mental disorders in older adults encompasses pharmacological interventions, electroconvulsive therapy, and psychosocial interventions. While the pharmacological and psychosocial interventions used to treat mental health problems and specific disorders may be identical for older and younger adults, characteristics unique to older adults may be important considerations in treatment selection.

Pharmacological Treatment

The special considerations in selecting appropriate medications for older people include physiological changes due to aging; increased vulnerability to side effects, such as tardive dyskinesia; the impact of polypharmacy; interactions with other comorbid disorders; and barriers to compliance. All are discussed below.

The aging process leads to numerous changes in physiology, resulting in altered blood levels of certain medications, prolonged pharmacological effects, and greater risk for many side effects (Kendell et al., 1981). Changes may occur in the absorption, distribution, metabolism, and excretion of psychotropic medications (Pollock & Mulsant, 1995).

As people age, there is a gradual decrease in gastrointestinal motility, gastric blood flow, and gastric acid production (Greenblatt et al., 1982). This slows the *rate* of absorption, but the overall *extent* of gastric absorption is probably comparable to that in other adults. The aging process is also associated with a decrease in total body water, a decrease in muscle mass, and an increase in adipose tissue (Borkan et al., 1983). Drugs that are highly lipophilic, such as neuroleptics, are therefore more likely to be accumulated in fatty tissues in older patients than they are in younger patients.

The liver undergoes changes in blood flow and volume with age. Phase I metabolism (oxidation, reduction, hydrolysis) may diminish or remain unchanged, while phase II metabolism (conjugation with an endogenous substrate) does not change with aging. Renal blood flow, glomerular surface area, tubular function, and reabsorption mechanisms all have been shown to diminish with age. Diminished renal excretion may lead to a prolonged half-life and the necessity for a lower dose or longer dosing intervals.

Pharmacodynamics, which refers to the drug's effect on its target organ, also can be altered in older individuals. An example of aging-associated pharmacodynamic change is diminished central cholinergic function contributing to increased sensitivity to the anticholinergic effects of many neuroleptics and antidepressants in older adults (Molchan et al., 1992).

Because of the pharmacokinetic and pharmacodynamic concerns presented above, it is often recommended that clinicians "start low and go slow" when prescribing new psychoactive medications for older adults. In other words, efficacy is greatest and side effects are minimized when initial doses are small and the rate of increase is slow. Nevertheless, the medication should generally be titrated to the regular adult dose in order to obtain the full benefit. The potential pitfall is that, because of slower titration and the concomitant need for more frequent medical visits, there is less likelihood of older adults receiving an adequate dose and course of medication.

Increased Risk of Side Effects

Older people encounter an increased risk of side effects, most likely the result of taking multiple drugs or having higher blood levels of a given drug. The increased risk of side effects is especially true for neuroleptic agents, which are widely prescribed as treatment for psychotic symptoms, agitation, and behavioral symptoms. Neuroleptic side effects include sedation, anticholinergic toxicity (which can result in urinary retention, constipation, dry mouth, glaucoma, and confusion), extrapyramidal symptoms (e.g., parkinsonism, akathisia, and dystonia), and tardive dyskinesia. Chapter 4 contains more detailed information about the side effects of neuroleptics.

Tardive dyskinesia is a frequent and persistent side effect that occurs months to years after initiation of neuroleptics. In older adults, tardive dyskinesia typically entails abnormal movements of the tongue, lips, and face. In a recent study of older outpatients treated with conventional neuroleptics the incidence of tardive dyskinesia after 12 months of neuroleptic treatment was 29 percent of the patients. At 24 and 36 months, the mean cumulative incidence was 50.1 percent and 63.1 percent, respectively (Jeste et al., 1995a). This study demonstrates the high risk of tardive dyskinesia in older patients even with low doses of conventional neuroleptics. Studies of younger adult patients reveal an annual cumulative incidence of tardive dyskinesia at 4 to 5 percent (Kane et al., 1993).

Unlike conventional neuroleptics, the newer atypical ones, such as clozapine, risperidone, olanzapine, and quetiapine, apparently confer several advantages with respect to both efficacy and safety. These drugs are associated with a lower incidence of extrapyramidal symptoms than conventional neuroleptics are. For clozapine, the low risk of tardive dyskinesia is well established (Kane et al., 1993). The incidence of tardive dyskinesia with other atypical antipsychotics is also likely to be lower than that with conventional neuroleptics because extrapyramidal symptoms have been found to be a risk factor for tardive dyskinesia in older adults (Saltz et al., 1991; Jeste et al., 1995a). The determination of exact risk of tardive dyskinesia with these newer drugs needs long-term studies.

Polypharmacy

In addition to the effects of aging on pharmacokinetics and pharmacodynamics and the increased risk of side effects, older individuals with mental disorders also are more likely than other adults to be medicated with multiple compounds, both prescription and nonprescription (i.e., polypharmacy). Older adults (over the age of 65) fill an average of 13 prescriptions a year (for original or refill prescriptions), which is approximately three times the number filled by younger individuals (Chrischilles et al., 1992). Polypharmacy greatly complicates effective treatment of mental disorders in older adults. Specifically, drug-drug interactions are of concern, both in terms of increasing side effects and decreasing efficacy of one or both compounds.

Treatment Compliance

Compliance with the treatment regimen also is a special concern in older adults, especially in those with moderate or severe cognitive deficits. Physical problems, such as impaired vision, make it likely that instructions may be misread or that one medicine may be mistaken for another. Cognitive impairment may also make it difficult for patients to remember whether or not they have taken their medication. Although in general, older patients are more compliant about taking psychoactive medications than other types of drugs (Cooper et al., 1982), when noncompliance does occur, it may be less easily detected, more serious, less easily resolved, mistaken for symptoms of a new disease, or even falsely labeled as "old-age" symptomatology. Accordingly, greater emphasis must be placed on strict compliance by patients in this age group (Lamy et al., 1992). Medication noncompliance takes different forms in older adults, that is, overuse and abuse, forgetting, and alteration of schedules and doses. The most common type of deliberate noncompliance among older adults may be the underuse of the prescribed drug, mainly because of side effects and cost considerations. Factors that contribute to medication noncompliance in older patients include inadequate information given to them regarding the necessity for drug treatment, unclear prescribing directions, suboptimal doctor-patient relationship, the large number of times per day drugs must be taken, and the large number of drugs that are taken at the same time (Lamy et al., 1992). Better compliance may be achieved by giving simple instructions and by asking specific questions to make sure that the patient understands directions.

Psychosocial Interventions

Several types of psychosocial interventions have proven effective in older patients with mental disorders, but the research is more limited than that on pharmacological interventions (see Klausner & Alexopoulos, in press). Both types are frequently used in combination. Most of the research has been restricted to psychosocial treatments for depression, although, as discussed below, there is mounting interest in dementia. For other mental disorders, psychosocial interventions found successful for younger adults are often tailored to older people in the practice setting without the benefit of efficacy research.

Despite the relative paucity of research, psychosocial interventions may be preferred for some older patients, especially those who are unable to tolerate, or prefer not to take, medication or who are confronting stressful situations or low degrees of social support (Lebowitz et al., 1997). The benefits of psychosocial interventions are likely to assume greater prominence as a result of population demographics: as the number of older people grows, progressively more older people in need of mental health treatment—especially the very old—are expected to be suffering from greater levels of comorbidity or dealing with the stresses associated with disability. Psychosocial interventions not only can help relieve the symptoms of a variety of mental disorders and related problems but also can play more diverse roles: they can help strengthen coping mechanisms, encourage (and monitor) patients' compliance with medications, and promote healthy behavior (Klausner & Alexopoulos, in press).

New approaches to service delivery are being designed to realize the benefits of established psychosocial interventions. Many older people are not comfortable with traditional mental health settings, partially as a result of stigma (Waters, 1995). In fact, many older people *prefer* to receive treatment for mental disorders by their primary care physicians, and most older people *do* receive such care in the primary care setting (Brody et al., 1997; Unutzer et al., 1997a). Since older people show willingness to accept psychosocial interventions in the primary care setting, new models are striving to integrate into the primary care setting the delivery of specialty mental health services. The section of this chapter on service delivery discusses new models in greater detail.

Gap Between Efficacy and Effectiveness

A problem common to both pharmacological and psychosocial interventions is the disparity between treatment efficacy, as demonstrated in randomized controlled clinical trials, and effectiveness in real-world settings. While this problem is certainly not unique to older people (see Chapter 2 for a broader discussion of the problem), this problem is especially significant for older people with mental disorders. Older people are often undertreated for their mental disorders in primary care settings (Unutzer et al., 1997a). When they do receive appropriate treatment, older people are more likely than other people to have comorbid disorders and social problems that reduce treatment effectiveness (Unutzer et al., 1997a). An additional overlay of barriers, including financing and systems of care, is discussed later in this chapter.

Depression in Older Adults

Depression in older adults not only causes distress and suffering but also leads to impairments in physical, mental, and social functioning. Despite being associated with excess morbidity and mortality, depression often goes undiagnosed and untreated. The startling reality is that a substantial proportion of older patients receive no treatment or inadequate treatment for their depression in primary care settings, according to expert consensus (NIH Consensus Development Panel on Depression in Late Life, 1992; Lebowitz et al., 1997). Part of the problem is that depression in older people is hard to disentangle from the many other disorders that affect older people, and its symptom profile is somewhat different from that in other adults. Depressive symptoms are far more common than full-fledged major depression. However, several depressive symptoms together represent a condition—explained below as "minor depression"—that can be as disabling as major depression (Unutzer et al., 1997a). Minor depression, despite the implications of the term, is *major* in its prevalence and impact. Eight to 20 percent of older adults in the community and up to 37 percent in primary care settings suffer from depressive symptoms. Treatment is successful, with response rates between 60 and 80 percent, but the response generally takes longer than that for other adults. In addition to reviewing information on prevalence and treatment, this section also discusses depression's course, barriers to diagnosis, interactions with physical disease, consequences, cost, and etiology.

Diagnosis of Major and "Minor" Depression

The term "major depression" refers to conditions with a major depressive episode, such as major depressive disorder, bipolar disorder, and related conditions. Major depressive disorder, the most common type of major depression in adults, is characterized by one or more episodes that include the following symptoms: depressed mood, loss of interest or pleasure in activities, significant weight loss or gain, sleep disturbance, psychomotor agitation or retardation, fatigue, feelings of worthlessness, loss of concentration, and recurrent thoughts of death or suicide. (For further discussion of the diagnosis of major depressive disorder, see Chapter 4.) Major depressive disorder cannot be diagnosed if symptoms last for less than 2 months after bereavement, among other exclusionary factors (DSM-IV).

Most older patients with symptoms of depression do not meet the full criteria for major depression. The new diagnostic entity of minor depression has been proposed to characterize some of these patients. "Minor depression," a subsyndromal form of depression, is not yet recognized as an official disorder, and DSM-IV proposes further research on it.

Minor depression is more frequent than major depression, with 8 to 20 percent of older community residents displaying symptoms (Alexopoulos, 1997; Gallo & Lebowitz, 1999). The diagnosis of minor depression is not yet standardized; the research criteria proposed in DSM-IV are the same as those for major depression, but a diagnosis would require fewer symptoms and less impairment. Minor depression, in fact, is not thought to be a single syndrome, but rather a heterogeneous group of syndromes that may signify either an early or residual form of major depression, a chronic, though mild, form of depression that does not present with a full array of symptoms at any one time, called dysthymia, or a response to an identifiable stressor (Judd et al., 1994; Pincus & Wakefield-Davis, 1997). Since depression is more difficult to assess and detect in older adults, research is needed on what clinical features might help identify older adults at increased risk for sustained depressive symptoms and suicide.

Both major and minor depression are associated with significant disability in physical, social, and role functioning (Wells et al., 1989). The degree of disability may not be as great with minor depression, but because of its higher prevalence, minor depression is associated with 51 percent more days lost from work than is major depression (Broadhead et al., 1990). Major and minor depression are associated with high health care utilization and poor quality of life (see Unutzer et al., 1997a, for a review).

Late-Onset Depression

Major or minor depression diagnosed with first onset later than age 60 has been termed *late-onset depression*. Late-onset depression is not a diagnosis; rather, it refers to a subset of patients with major or minor depression whose later age at first onset imparts slightly different clinical characteristics, suggesting the possibility of distinct etiology. Late-onset depression shares many clinical characteristics with early-onset depression, yet some distinguishing features exist. Patients with late-onset depression display greater apathy (Krishnan et al., 1995) and less lifetime personality dysfunction (Abrams et al., 1994). Cognitive deficits may be more prominent, with more impaired executive and memory functioning (Salloway et al., 1996) and greater medial temporal lobe abnormalities on magnetic resonance imaging, similar to those seen in dementia (Greenwald et al., 1997). Other studies, however, have shown no differences in cognition between patients with late- and early-onset depression (Holroyd & Duryee, 1997). The risk of recurrence of depression is relatively high among patients with onset of depression after the age of 60 (Reynolds, 1998).

Risk factors for late-onset depression, based on results of prospective studies, include widowhood (Bruce et al., 1990; Zisook & Shuchter, 1991; Harlow et al., 1991; Mendes de Leon et al., 1994), physical illness (Cadoret & Widmer, 1988; Harlow et al., 1991; Bachman et al., 1992), educational attainment less than high school (Wallace & O'Hara, 1992; Gallo et al., 1993), impaired functional status (Bruce & Hoff, 1994), and heavy alcohol consumption (Saunders et al., 1991).

Prevalence and Incidence

Estimates of the prevalence of major depression vary widely, depending on the definition and the procedure used for counting persons with depression (Gallo & Lebowitz, 1999). Researchers applying DSM criteria for major depression have found 1-year U.S. prevalence rates of about 5 percent or less in older people (Gurland et al., 1996). The prevalence of major depression declines with age, while depressive symptoms increase (symptoms that now might warrant classification as minor depression). Romanoski and colleagues, on the basis of psychiatric interviews of adults in the Baltimore Epidemiologic Catchment Area, showed that major depression declined with advancing age (Romanoski et al., 1992). Prevalence estimates derived from *symptom* scales are consistent with the clinical impression that prevalence of depressive symptoms increases with advancing age. Depressive symptoms and syndromes have been identified in 8 to 20 percent of older community residents (Alexopoulos, 1997; Gallo & Lebowitz, 1999) and 17 to 35 percent of older primary care patients (Gurland et al., 1996).

Several incidence studies based on DSM criteria reflect a similar pattern of decline in rates of major depression with advancing age (Eaton et al., 1989; Eaton et al., 1997). The 13-year followup of the participants of the Baltimore Epidemiologic Catchment Area (ECA) sample revealed, however, that the distribution of the incidence of DSM-based major depression across the life span was bimodal, with a primary peak in the fourth decade and a secondary peak in the sixth decade (Eaton et al., 1997). In contrast to studies based on DSM criteria, several incidence studies report increased rates of depressive symptoms with age. A Swedish study reported that rates of depressive symptoms were highest in the older age groups and that rates of depression had increased in the interval from 1947–1957 to 1957–1972 (Hagnell et al., 1982). Incidence studies reveal an increased risk of depression among women as they age, consistent with findings based on prevalence surveys (Hagnell et al., 1982; Eaton et al., 1989; Gallo et al., 1993).

Thus, both prevalence and incidence studies that rely on DSM-based diagnosis of major depression suggest a decline with age, whereas symptom-based assessment studies show increased rates of depression among older adults, especially women. Evidence that older adults are less likely than younger persons to report feelings of dysphoria (i.e., sadness, unhappiness, or irritability) suggests that the standard criteria for depression may be more difficult to apply to older adults (Gallo et al., 1994) or that older adults are disinclined to report such feelings.

Other mood disorders, such as dysthymia, bipolar disorder, and hypomania,[1] also are present in older individuals. Little difference has been found in the prevalence of affective disorders between African Americans and whites over the age of 65 (Weissman et al., 1991). The prevalence of bipolar disorder among people aged 65 and over is reportedly less than 1 percent (Robins & Regier, 1991). Approximately 5 to 10 percent of older patients presenting with mood disorders are manic or hypomanic (Yassa et al., 1988). However, these mood disorders will not be the focus of this section of the report, as they are much less common in older adults than depression.

Barriers to Diagnosis and Treatment

The underdiagnosis and undertreatment of depression in primary care represent a serious public health problem (NIH Consensus Development Panel on Depression in Late Life, 1992). One study found that only about 11 percent of depressed patients in primary care received adequate antidepressant treatment (in terms of dose and duration of pharmacotherapy), while 34 percent received inadequate treatment and 55 percent received no treatment (Katon et al., 1992).

There are many barriers to the diagnosis of depression in late life. Some of these barriers reflect the nature of the disorder: depression occurs in a complex medical and psychosocial context. In the elderly, the signs and symptoms of major depression are frequently attributed to "normal aging," atherosclerosis, Alzheimer's disease, or any of a host of other age-associated afflictions. Psychosocial antecedents such as loss, combined with decrements in physical health and sensory impairment, can also divert attention from clinical depression.

Another reason for the underdiagnosis is that older patients are less likely to report symptoms of dysphoria and worthlessness, which are often considered hallmarks of the diagnosis of depression. The consequences of underdiagnosis of this subset of patients can be severe. On the basis of a followup of older adults in the Baltimore Epidemiologic Catchment Area sample, persons with depressive symptoms (e.g., sleep and appetite disturbance) without sadness (e.g., hopelessness, worthlessness, thoughts of death, wanting to die, or suicide) were at increased risk for subsequent functional impairment, cognitive impairment, psychological distress, and death over the course of the 13-year interval (Gallo et al., 1997).

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[1] Hypomania is marked by abnormally elevated mood, but the symptoms are not severe enough for mania (see Chapter 4).

Other barriers to diagnosis are patient related. Depression can and frequently does amplify physical symptoms, distracting patients' and providers' attention from the underlying depression; and many older patients may deny psychological symptoms of depression or refuse to accept the diagnosis because of stigma. This appears to be particularly the case with older men, who also have the highest rates of suicide in later life (Hoyert et al., 1999).

Provider-related factors also appear to play a role in underdetection of depression and suicide risk. Providers may be reluctant to inform older patients of a diagnosis of depression, owing to uncertainty about diagnosis, reluctance to stigmatize, uncertainty about optimal treatment, concern about medication interactions or lack of access to psychiatric care, and continuing concern about the effectiveness and cost-effectiveness of treatment intervention (NIH Consensus Development Panel on Depression in Late Life, 1992; Unutzer et al., 1997a).

Societal stereotypes about aging also can hamper efforts to identify and diagnose depression in late life. Many people believe that depression in response to the loss of a loved one, increased physical limitations, or changing societal role is an inevitable part of aging. Even physicians appear to hold such stereotyped views. Three-quarters of physicians in one study thought that depression "was understandable" in older persons (Gallo et al., in press), consistent with other studies (Bartels et al., 1997). Suicidal thoughts are sometimes considered a normal facet of old age. These mistaken beliefs can lead to underreporting of symptoms by patients and lack of effort on the part of family members to seek care for patients.

Finally, the health care system itself is increasingly restricting the time spent in patient care, forcing mental health concerns to compete with comorbid general medical conditions. Primary care physicians often report feeling too pressured for time to investigate depression in older people (Glasser & Gravdal, 1997). Given the inseparability of mental and general health in later life particularly, this trend is worrisome.

Course

Across the life span, the course of depression is marked by recurrent episodes of depression followed by periods of remission. In late life, the course of depression tends to be more chronic than that in younger adults (Alexopoulos & Chester, 1992; Callahan et al., 1994; Cole & Bellavance, 1997). This means that recurrences extend for longer duration, while intervals of remission are shorter. It also means that cycles of recurrence and remission persist over a longer period of time. Patients' response to treatment is highly variable, and the determinants of treatment response and its temporal profile are the subjects of intense research (Reynolds & Kupfer, 1999). A slower, less consistent response, which suggests a higher probability of relapse, is related to older age, presence of acute and chronic stressors, lower levels of perceived social support, higher levels of pretreatment anxiety, and greater biologic dysregulation as reflected in higher levels of rapid eye movement sleep (Dew et al., 1997). The temporal profile of the initial treatment response also may provide important clues about which patients are likely to fare well on maintenance treatment and which ones are likely to have a brittle treatment response and stormy long-term course.

A recent update of the NIH Consensus Development Conference on the Diagnosis and Treatment of Late-Life Depression emphasized the need for more data to guide long-term treatment planning, especially in patients 70 years and older with major depression (Lebowitz et al., 1997). Little is currently known about differences, if any, in speed and rate of remission, relapse, recovery, and recurrence in patients aged 60 to 69 and those aged 70 and above. In a study at the University of Pittsburgh, two groups of patients (ages

60 to 69 and 70+) showed comparable times to remission and recovery, as well as similar absolute rates of remission during acute therapy, relapse during continuation therapy, and recovery. However, patients aged 70 and older experienced a significantly higher rate of recurrence during the first year of maintenance therapy (Reynolds, 1998). Thus, the course of depression and its interaction with treatment are influenced by age. This highlights the importance of research targeted at older age groups instead of reliance on extrapolations from younger patients.

Interactions With Somatic Illness

Late-life mental disorders are often detected in association with somatic illness (Reynolds & Kupfer, 1999). The prevalence of clinically significant depression in later life is estimated to be highest—approximately 25 percent—among those with chronic illness, especially with ischemic heart disease, stroke, cancer, chronic lung disease, arthritis, Alzheimer's disease, and Parkinson's disease (Borson et al., 1986; Blazer, 1989; Oxman et al., 1990; Callahan et al., 1994; Beekman et al., 1995; Borson, 1995).

The relationship between somatic illness and mental disorders is likely to be reciprocal, but the mechanisms are far from understood. Biological and psychological factors are thought to play a role (Unutzer et al., 1997a). The nature and course of late-life depression can be greatly affected by the coexistence of one or more other medical conditions.

Insomnia and sleep disturbance play a large role in the clinical presentation of older depressed patients. Sleep complaints over time in community-residing older people have been found to vary with the intensity of depressive symptoms (Rodin et al., 1988). Sleep disturbances in older men and women have also been recently linked to poor health, depression, angina, limitations in activities of daily living, and chronic use of benzodiazepines (Newman et al., 1997). Furthermore, persistent or residual sleep disturbance in older patients with prior depressive episodes predicts a less successful maintenance response to pharmacotherapy (Buysse et al., 1996). The prevalence of chronic, primary insomnia in older adults is estimated at 5 to 10 percent (Ohayon et al., 1996). Relatively little is known about the etiology or pathophysiology of chronic primary insomnia and why it constitutes a risk factor for depression in older adults. An important issue for further research is whether effective treatment for chronic insomnia could prevent the subsequent development of clinical depression in midlife and later.

Consequences of Depression

The most serious consequence of depression in later life—especially untreated or inadequately treated depression—is increased mortality from either suicide or somatic illness. Older persons (65 years and above) have the highest suicide rates of any age group. The suicide rate for individuals age 85 and older is the highest, at about 21 suicides per 100,000, a rate almost twice the overall national rate of 10.6 per 100,000 (CDC, 1999). The high suicide rate among older people is largely accounted for by white men, whose suicide rate at age 85 and above is about 65 per 100,000 (CDC, 1999). Trends from 1980 to 1992 reveal that suicide rates are increasing among more recent cohorts of older persons (Kachur et al., 1995). Since national statistics are unlikely to include more veiled forms of suicide, such as nursing home residents who stop eating, estimates are probably conservative.

Suicide in older adults is most associated with late-onset depression: among patients 75 years of age and older, 60 to 75 percent of suicides have diagnosable depression (Conwell, 1996). Using a "psychological autopsy," Conwell and coworkers investigated all suicides within a geographical region and found that with increasing age, depression was more likely to be unaccompanied by other conditions such as substance abuse (Conwell et al., 1996). While thoughts of death may be developmentally expected in older adults, suicidal thoughts are not. From a stratified sample of primary care patients over age 60, Callahan and colleagues estimated the prevalence of specific suicidal thoughts at 0.7 to 1.2 percent (Callahan et al., 1996b). Unfortunately, no demographic or clinical variables distinguished depressed suicidal patients from depressed nonsuicidal patients (Callahan et al., 1996b).

Swedish researchers found much higher rates of suicidal ideation after interviewing adults aged 85 years and older. They found a 1-month prevalence of any suicidal feelings in 9.6 percent of men and 18.7 percent of women (Skoog et al., 1996). Suicidal feelings were strongly associated with depression. For example, 6.2 percent of the participants who did not meet criteria for depression or anxiety reported suicidal thoughts, while almost 50 percent of those meeting criteria for depression reported such thoughts. The higher prevalence of suicidal feelings in this study, compared with that cited earlier, is likely due to the older age of subjects and to methodological differences.

Studies of older persons who have committed suicide have revealed that older adults had seen their physician within a short interval of completing suicide, yet few were receiving mental health treatment. Caine and coworkers studied the records of 97 adults aged 50 years and older who completed suicide (Caine et al., 1996). Of this group, 51 had seen their primary care physician within 1 month of the suicide. Forty-five had psychiatric symptoms. Yet in only 29 of the 45 individuals were symptoms recognized, in only 19 was treatment offered, and in only 2 of these 19 cases was the treatment rendered considered adequate. Treatment was deemed inadequate if an incorrect medicine (such as a benzodiazepine for severe major depression) or inadequate dose was prescribed. This line of research highlights important opportunities for suicide prevention.

Depression also can lead to increased mortality from other diseases, such as heart disease and possibly cancer. How depression exerts these effects is not yet understood. In nursing home patients, major depression increases the likelihood of mortality by 59 percent, independent of physical health measures (Rovner, 1993). In the case of myocardial infarction, depression elevates mortality risk fivefold (Frasure-Smith et al., 1993, 1995). Depression also has been linked to the onset of cancer, but results have been inconsistent. Yet a new epidemiological study, considered the most compelling to date, finds that chronic depression (lasting an average of about 4 years) raises the risk of cancer by 88 percent in older people (Penninx et al., 1998). Thus, increased understanding of depression in older people may be, literally, a matter of life and death.

Cost

The high prevalence of depressive syndromes and symptoms in older adults exacts a large economic toll. Depression as a whole for all age groups is one of the most costly disorders in the United States (Hirschfeld et al., 1997). The direct and indirect costs of depression have been estimated at $43 billion each year, not including pain and suffering and diminished quality of life (Finkelstein et al., 1996). Late-life depression is particularly costly because of the excess disability that it causes and its deleterious interaction with physical health. Older primary care patients with depression visit the doctor and emergency room more often, use more medication, incur higher outpatient charges, and stay longer at the hospital (Callahan et al., 1994; Cooper-Patrick et al., 1994; Callahan & Wolinsky, 1995; Unutzer et al., 1997b).

Etiology of Late-Onset Depression

Despite major advances, the etiology of depression occurring at *any* age is not fully understood, although biological and psychosocial factors clearly play an important and interactive role.

With respect to late-onset depression, several risk factors have been identified. Persistent insomnia, occurring in 5 to 10 percent of older adults, is a known risk factor for the subsequent onset of new cases of major depression both in middle-aged and older persons (Ford & Kamerow, 1989). Grief following the death of a loved one also is an important risk factor for both major and minor depression. At least 10 to 20 percent of widows and widowers develop clinically significant depression during the first year of bereavement. Without treatment, such depressions tend to persist, becoming chronic and leading to further disability and impairments in general health (Zisook & Shuchter, 1993). A final pathway to late-onset depression, suggested by computed tomography and magnetic resonance imaging studies, may involve structural, neuroanatomic factors. Enlarged lateral ventricles, cortical atrophy, increased white matter hyperintensities, decreased caudate size, and vascular lesions in the caudate nucleus appear to be especially prominent in late-onset depression associated with vascular risk factors (Ohayon et al., 1996; Baldwin & Tomenson, 1995). These findings have generated the vascular hypothesis of late-onset depression; namely, that even in the absence of a clear stroke, disorders that cause vascular damage, such as hypertension, coronary artery disease, and diabetes mellitus, may induce cerebral pathology that constitutes a vulnerability for depression (Alexopoulos et al., 1997; Steffens & Krishnan, 1998).

Treatment of Depression in Older Adults

A broad array of effective treatments, both pharmacological and psychosocial, exists for depression. Despite the pervasiveness of depression and the existence of effective treatments, a substantial fraction of patients receive either no treatment or inadequate treatment, as described earlier. Some of the barriers relate to underdiagnosis, while others relate to treatment where there are patient, provider, and clinical barriers (for more details see Unutzer et al., 1996).

Pharmacological Treatment

There is consistent evidence that older patients, even the very old, respond to antidepressant medication (Reynolds & Kupfer, 1999). About 60 to 80 percent of older patients respond to treatment, while the placebo response rate is about 30 to 40 percent (Schneider, 1996). These rates are comparable to those in other adults (see Chapter 4). Treatment response is typically defined by a significant reduction—usually 50 percent or greater—in symptom severity. Yet because patients 75 years old and older typically have higher prevalence of medical comorbidity, both they and their physicians are often reluctant to add another medication to an already complex regimen in a frail individual. However, newer antidepressants are less frequently associated with factors contraindicating their use. Moreover, because the very old are also at high risk for adverse medical outcomes of depression and for suicide, treatment may be favored. Despite the availability of effective treatments, a minority of patients properly diagnosed with depression receive adequate dosage and duration of pharmacotherapy, as noted earlier.

In general, pharmacological treatment of depression in older people is similar to that in other adults, but the selection of medications is more complex because of side effects and interactions with other medications for concomitant somatic disorders. Treatment of minor depression is generally the same as treatment for major depression, but there is not a large body of evidence to support this practice. Studies are under way to identify effective pharmacological treatments for minor depression (Lebowitz et al., 1997).

The following paragraphs describe the major classes of medications for treatment of depression in older adults. They focus on side effects and other concerns that distinguish the treatment of depression in older adults from that in younger ones.

Tricyclic Antidepressants

Tricyclic antidepressants (TCAs) have been widely used to treat depressed patients of all ages. Alexopoulos and Salzman (1998) reviewed studies of TCAs in older depressed patients and concluded that these compounds are similar in efficacy across the age spectrum, but the side effect profiles differ considerably. Widespread use of the TCAs in older adults is limited by adverse reactions. While anticholinergic effects such as dry mouth, urinary retention, and constipation can be annoying in younger adults, they can lead to severe problems in older adults. For example, constipation can lead to impaction, and dry mouth can prevent the wearing of dentures. The anticholinergic effects of the TCAs may also cause tachycardia or arrhythmias and can further compromise preexisting cardiac disease (Roose et al., 1987; Glassman et al., 1993). Central anticholinergic effects may result in acute confusional states or memory problems in the depressed older adult (Branconnier et al., 1982). Orthostatic hypotension, which may lead to falls and hip fractures, is also a concern when the TCAs are administered. Nevertheless, TCAs are still frequently used in older adults.

Selective Serotonin Reuptake Inhibitors and Other Newer Antidepressants

Selective serotonin reuptake inhibitors (SSRIs) such as fluoxetine, paroxetine, and sertraline, whose use is increasing across age groups, may be especially useful in the treatment of late-life depression, because these agents are reported to have fewer anticholinergic and cardiovascular side effects than the TCAs. The more commonly observed side effects with SSRIs include sexual dysfunction and gastrointestinal effects such as nausea, vomiting, and loose stools. Treatment with the SSRIs may also produce insomnia, anxiety, and restlessness. The few studies that have examined the efficacy of these compounds in older adults have shown efficacy similar to the TCAs and fewer side effects (see Small & Salzman, 1998, for a review). While the relative efficacy of SSRIs and TCAs is still debated, SSRIs are easier to prescribe because of simpler dosing patterns and more manageable side effects.

One concern when prescribing the SSRIs in older adults is the potential for drug-drug interactions. This is of clinical importance since older adults commonly receive a large number of medications. The SSRIs vary in their inhibition of the cytochrome p450 family of isoenzymes. Knowledge of these patterns of inhibition in the SSRIs and other medications commonly used in older adults (such as other psychoactive compounds, calcium channel blockers, or warfarin) can help to avoid or minimize interactions. Other newer non-SSRI antidepressants (venlafaxine, bupropion, trazodone, and nefazodone) are often suggested for treating later life depression because their side effects are better tolerated by older adults.

Some compounds that are useful in other individuals may be less useful for treatment of older patients. For example, despite evidence of the efficacy of monamine oxidase inhibitors (see Alexopoulos & Salzman, 1998, for a review), clinical use is often restricted to patients who are refractory to other antidepressant drugs. This is due to potentially life-threatening pharmacodynamic interactions with sympathomimetic drugs or tyramine-containing foods and beverages. The sympathomimetic amines (e.g., phenylpropanolamine and pseudoephedrine) may be present in over-the-counter decongestant products that older patients are prone to self-administer. An additional concern is the risk of orthostatic hypotension, which occurs even at therapeutic doses (Alexopoulos & Salzman, 1998). In addition, bupropion has been shown in older patients to be as effective as TCAs (Branconnier et al., 1983; Kane et al., 1983). Although generally well tolerated, its use requires added caution because of an increased risk of seizures and thus should be avoided in patients with seizure disorder or focal central nervous system disease. Its advantages include a relatively low incidence of cardiovascular complications and a lack of confusion.

Multimodal Therapy

Combining pharmacotherapy with psychosocial interventions also appears to be effective in older depressed patients. A high response rate of about 80 percent was found for acute and continuation treatment with combined nortriptyline and interpersonal psychotherapy. The response rate was similar between so-called "young old" patients (primarily in their 60s and early 70s) and patients in their 30s and 40s (Reynolds et al., 1996). Yet older patients showed a somewhat longer time to remission than did other patients (about 2 weeks longer) and twice the rate of relapse during continuation treatment (about 15 percent versus 7 percent). However, because the trial was not controlled, it is not known whether multimodal treatment was more effective than either pharmacological or psychosocial treatment alone. Treatment resistance—defined by the lack of recovery in spite of combined treatment with nortriptyline and interpersonal psychotherapy—was seen in about 18 percent of older patients with recurrent major depression (nonpsychotic unipolar depression) (Little et al., 1998). Nortriptyline and interpersonal psychotherapy (IPT) have been shown to be effective maintenance treatments for late-life depression. After 3 years of comparing various treatments, the percentage of older adults who did not experience recurrence were 57 percent of older adults receiving nortriptyline, 36 percent receiving IPT, and 80 percent of those receiving nortriptyline plus IPT. Those receiving a placebo and routine clinical visits had a 90 percent recurrence rate (Reynolds et al., 1999).

Course of Treatment

Although 60 to 80 percent of older patients with moderate to severe unipolar depression[2] can be expected to respond well to antidepressant treatment (especially combined treatment with medication and psychotherapy), the clinical response to antidepressant treatment in later life follows a variable course, with a median time to remission of 12 weeks (J. L. Cummings & D. J. Kupfer, personal communication, 1999). Thus, treatment response takes 1 month or more longer than that for other adults, for whom treatment response takes an average of 6 to 8 weeks (see Chapter 4). In addition to highly variable trajectories to recovery, reliable prediction of response status (recovery/nonrecovery) is generally not possible in older adults before 4 to 5 weeks of treatment. The delayed onset of antidepressant activity in older adults leads to unique problems. Suffering and disability are prolonged, which often reduces compliance and may increase risk for suicide. The development of strategies to accelerate treatment response and to improve the early identification of nonresponders would be an important advance (Reynolds & Kupfer, 1999).

Data from naturalistic studies have identified several predictors of relapse and recurrence in late-life depression, including a history of frequent episodes, first episode after age 60, concurrent somatic illness, especially a history of myocardial infarction or vascular disease, high pretreatment severity of depression and anxiety, and cognitive impairment, especially frontal lobe dysfunction. These factors appear to interact with low treatment intensity—that is, at dosage and duration below recommended levels—in determining more severe courses of illness. Despite the evidence that high treatment intensity is effective in preventing relapse and recurrence (Reynolds et al., 1995), naturalistic studies have shown that intensity of treatment prescribed by psychiatrists begins to decline within 16 weeks of entry and approximately 10 weeks prior to recovery (Alexopoulos et al., 1996). Residual symptoms of excessive anxiety and worrying predict early recurrence after tapering continuation treatment in older depressed patients (Meyers, 1996).

Although progress has been made in identifying effective pharmacological and combined treatments for late-life depression, there is a need for more outcome studies with newer antidepressants. In addition, studies examining effectiveness in real-world settings—rather than in clinical trials conducted in academic clinical sites—are particularly crucial in the older population because of medical comorbidity and provision of care in primary, rather than specialty, care.

Electroconvulsive Therapy

Electroconvulsive therapy (ECT) is regarded as an effective intervention for some forms of treatment-resistant depression across the life cycle (NIH & NIMH Consensus Conference, 1985; Depression Guideline Panel, 1993). It may offer a particularly attractive benefit:risk ratio in older persons with depression (NIH Consensus Development Panel on Depression in Late Life, 1992; Sackeim, 1994). Chapter 4 reviews research on ECT and considers risk-benefit issues and controversy surrounding them. As described there, ECT entails the electrical induction of seizures in the brain, administered during a series of 6 to 12 treatment sessions on an inpatient or outpatient basis. Practice guidelines recommend that ECT should be reserved for severe cases of depression, particularly with active suicidal risk or psychosis; patients unresponsive to medications; and those who cannot tolerate medications (NIH & NIMH Consensus Conference, 1985; Depression Guideline Panel, 1993). For those patients, the response rate to ECT is on the order of 50 to 70 percent, and there is no evidence that ECT is any less effective in older individuals than younger ones (Sackeim, 1994; Weiner & Krystal, 1994). ECT is advantageous for older people with depression because of the special problems they encounter with medications, including sensitivity to anticholinergic toxicity, cardiac conduction slowing, and hypotension (see above). Although the newer antidepressants offer a more favorable side-effect profile than do the older tricyclics, their efficacy in melancholic depression, for which ECT is particularly helpful (Rudorfer et al., 1997), is not yet firmly established. Moreover, as noted earlier, older adults respond more slowly than younger ones to antidepressant medications, rendering the faster onset of action of ECT another advantage in the older patient (Markowitz et al., 1987). Immobility and reduced food and fluid intake in the older person with depression may pose a greater imminent physical health risk than would typically be the case in a younger patient, again strengthening the case for considering ECT early in the treatment hierarchy (Sackeim, 1994).

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[2] Unipolar depression refers to the depression in patients with major depressive disorders but not to the depression in patients with bipolar disorders.

Although the clinical effectiveness of ECT is documented and acknowledged, the treatment often is associated with troubling side effects, principally a brief period of confusion following administration and a temporary period of memory disruption (Rudorfer et al., 1997). As described in Chapter 4, there may also be longer term memory losses for the time period surrounding the use of ECT. Although the exception rather than the rule, persistent memory loss following ECT is reported. Its actual incidence is unknown. There are no absolute medical contraindications to ECT. However, a recent history of myocardial infarct, irregular cardiac rhythm, or other heart conditions suggests the need for caution due to the risks of general anesthesia and the brief rise in heart rate, blood pressure, and load on the heart that accompany ECT administration. On the other hand, the safety of ECT is enhanced by the time-limited nature of treatment sessions, which enables this intervention to be administered under controlled conditions, for example, with a cardiologist or other specialist in attendance. Following completion of a course of ECT, maintenance treatment, typically with antidepressant or mood-stabilizing medication or less frequent maintenance ECT, in most cases is required to prevent relapse (Rudorfer et al., 1997).

Psychosocial Treatment of Depression

Most research to date on psychosocial treatment of mental disorders has concentrated on depression. These studies suggest that several forms of psychotherapy are effective for the treatment of late-life depression, including cognitive-behavioral therapy, interpersonal psychotherapy, problem-solving therapy, brief psychodynamic psychotherapy, and reminiscence therapy, an intervention developed specifically for older adults on the premise that reflection upon positive and negative past life experiences enables the individual to overcome feelings of depression and despair (Butler, 1974; Butler et al., 1991). Group and individual formats have been used successfully.

A meta-analysis of 17 studies of cognitive, behavioral, brief psychodynamic, interpersonal, reminiscence, and eclectic therapies for late-life depression found treatment to be more effective than no treatment or placebo (Scogin & McElreath, 1994). The following paragraphs spotlight some of the key studies incorporated into this meta-analysis and provide evidence from newer studies.

Cognitive-behavioral therapy is designed to modify thought patterns, improve skills, and alter the emotional states that contribute to the onset, or perpetuation, of mental disorders. In a 2-year followup study of cognitive-behavioral therapy, 70 percent of all patients studied no longer met criteria for major depression and maintained treatment gains (Gallagher-Thompson et al., 1990). In another trial, group cognitive therapy was found to be effective. Older patients with major depression partially randomized to receive group cognitive therapy with alprazolam (a benzodiazepine) or group cognitive therapy with placebo had more improvement in depressed mood and sleep efficiency than patients who received alprazolam alone or placebo alone (Beutler et al., 1987). Cognitive-behavioral therapy also has been demonstrated to be effective in other late-life disorders, including anxiety disorders (Stanley et al., 1996; Beck & Stanley, 1997). Cognitive-behavioral therapy's effectiveness for mood symptoms in Alzheimer's disease is discussed in the section on psychosocial treatments of Alzheimer's disease.

Problem-solving therapy postulates that deficiencies in social problem-solving skills enhance the risk for depression and other psychiatric symptoms. Through improving problem-solving skills, older patients are given the tools to enable them to cope with stressors and thereby experience fewer symptoms of psychopathology (Hawton & Kirk, 1989). Problem-solving therapy has been found effective in the treatment of depression of older patients. For example, problem-solving therapy was found to significantly reduce symptoms of major depression, leading to the greatest improvement in a randomized controlled study comparing problem-solving therapy, reminiscence therapy, and placement on a waiting list for treatment (Arean et al., 1993). In a randomized study of depressed younger primary care patients, six sessions of problem-solving therapy were as effective as amitriptyline, with about 50 to 60 percent of patients in each group recovering (Mynors-Wallis et al., 1995).

Interpersonal psychotherapy was initially designed as a time-limited treatment for midlife depression. It focuses on grief, role disputes, role transitions, and interpersonal deficits (Klerman et al., 1984). This form of treatment may be especially meaningful for older patients given the multiple losses, role changes, social isolation, and helplessness associated with late-life depression. Controlled trials suggest that interpersonal psychotherapy alone, or in combination with pharmacotherapy, is effective in all phases of treatment for late-life major depression. Interpersonal psychotherapy was as effective as the antidepressant nortriptyline in depressed older outpatients, and both were superior to placebo (Sloane et al., 1985; Reynolds et al., 1992; Schneider, 1995). In an open trial, a treatment protocol combining interpersonal psychotherapy with nortriptyline and psychoeducational support groups led to minimal attrition and high remission rates (approximately 80 percent) in older patients with recurrent major depression (Reynolds et al., 1992, 1994). Finally, interpersonal psychotherapy also is effective in the treatment of depression following bereavement (Pasternak et al., 1997).

Brief psychodynamic therapy, typically of 3 to 4 months' duration, also is successful in older depressed patients. Brief psychodynamic therapy is distinguished from traditional psychodynamic therapy primarily by duration of treatment. The goals of brief psychodynamic therapy vary according to patients' medical health and function. In disabled older people, the purpose of psychodynamic psychotherapy is to facilitate mourning of lost capacities, promote acceptance of physical limitations, address fears of dependency, and promote resolution of interpersonal difficulties with family members (Lazarus & Sadavoy, 1996). In older patients who are not disabled, psychodynamic psychotherapy deals with the resolution of interpersonal conflicts, adaptation to loss and stress, and the reconciliation of personal accomplishments and disappointments (Pollock, 1987). Brief psychodynamic therapy has been found to be as effective as cognitive-behavioral therapy in reducing symptoms of late-life major depression. An early study found brief psychodynamic therapy to yield higher relapse and recurrence rates than did cognitive and behavioral therapy (Gallagher & Thompson, 1982). However, with a greater number of patients, brief psychodynamic therapy was determined to be as effective as cognitive and behavioral therapy (and superior to being on a waiting list) in preventing recurrences of major depression up to 2 years after treatment (Gallagher-Thompson et al., 1990).

Alzheimer's Disease

Alzheimer's disease, a disorder of pivotal importance to older adults, strikes 8 to 15 percent of people over the age of 65 (Ritchie & Kildea, 1995). Alzheimer's disease is one of the most feared mental disorders because of its gradual, yet relentless, attack on memory. Memory loss, however, is not the only impairment. Symptoms extend to other cognitive deficits in language, object recognition, and executive functioning.[3] Behavioral symptoms—such as psychosis, agitation, depression, and wandering—are common and impose tremendous strain on caregivers. Diagnosis is challenging because of the lack of biological markers, insidious onset, and need to exclude other causes of dementia.

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[3] Executive functioning refers to the ability to plan, organize, sequence, and abstract.

This section covers assessment and diagnosis, behavioral symptoms, course, prevalence and incidence, cost, etiology, and treatment. It features Alzheimer's disease because it is the most prevalent form of dementia. However, many of the issues raised also pertain to other forms of dementia, such as multi-infarct dementia, dementia of Parkinson's disease, dementia of Huntington's disease, dementia of Pick's disease, frontal lobe dementia, and others.

Assessment and Diagnosis of Alzheimer's Disease

Mild Cognitive Impairment

Declines in cognitive functioning have been identified both as part of the normal process of aging and as an indicator of Alzheimer's disease. DSM-IV first designated this as "age-related cognitive decline" and, more recently, as "mild cognitive impairment" (MCI). MCI characterizes those individuals who have a memory problem but do not meet the generally accepted criteria for Alzheimer's disease such as those issued by the National Institute of Neurological and Communicative Disorders and Stroke–Alzheimer's Disease and Related Disorders Association or DSM-IV. MCI is important because it is known that a certain percentage of patients will convert to Alzheimer's disease over a period of time (probably in the range of 15 to 20 percent per year). Thus, if such individuals could be identified reliably, treatments could be given that would delay or prevent the progression to diagnosed Alzheimer's disease. This is the rationale for the Alzheimer's Disease Cooperative Study trial of vitamin E or donepezil for MCI, which began in 1999, and it is also the basis for the use of neuroimaging in early diagnosis. The evaluation of MCI spans the boundary between normal aging and Alzheimer's disease, and this topic is being evaluated in a number of research groups.

The diagnosis of Alzheimer's disease depends on the identification of the characteristic clinical features and on the exclusion of other common causes of dementia. There are currently no biological markers for Alzheimer's disease except for pathological verification by biopsy or at autopsy (or through rare autosomal dominant mutations). With the reliance on clinical criteria and the need for exclusion of other causes of dementia, the current approach to Alzheimer's disease diagnosis is time- and labor-intensive, costly, and largely dependent on the expertise of the examiner. Although genetic risk factors, such as Apo-E status (see etiology section), give some indication of the relative risk for Alzheimer's disease, they are as yet rarely useful on an individual basis.

The diagnosis of Alzheimer's disease not only requires the presence of memory impairment but also another cognitive deficit, such as language disturbance or disturbance in executive functioning. The diagnosis also calls for impairments in social and occupational functioning that represent a significant functional decline (DSM-IV). The other causes of dementia that must be ruled out include cerebrovascular disease, Parkinson's disease, Huntington's disease, subdural hematoma, normal-pressure hydrocephalus, brain tumor, systemic conditions (e.g., hypothyroidism, vitamin B_{12} or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis, HIV infection), and substance-induced conditions.

Some diagnostic schemes distinguish between possible, probable, and definite Alzheimer's disease (McKhann et al., 1984). With these criteria, probable Alzheimer's disease is confirmed to be Alzheimer's disease at autopsy with 85 to 90 percent accuracy (Galasko et al., 1994). Definite Alzheimer's disease can only be diagnosed pathologically through biopsy or at autopsy. The pathological hallmarks of Alzheimer's disease are neurofibrillary tangles (intracellular aggregates of a cytoskeletal protein called tau found in degenerating or dead brain cells) and neuritic plaques (extracellular deposits largely made up of a protein called amyloid β-peptide) (Cummings, 1998b). (See Figure 5-2.)

The diagnosis of dementia can be complicated by the possibility of other disorders that coexist with, or share features of, Alzheimer's disease. For example,

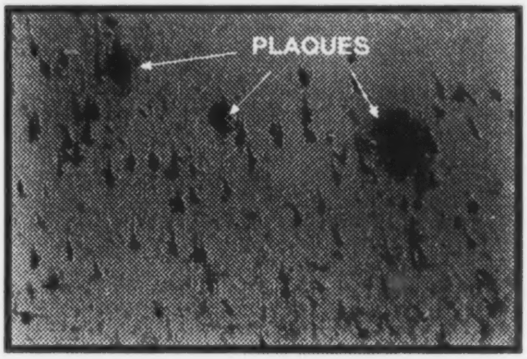

Figure 5-2. Neuritic plaques and many neurofibrillary tangles in the hippocampus of an Alzheimer's disease patient. (Photo courtesy of Peter Davies, Ph.D., Department of Pathology, Albert Einstein College of Medicine.)

delirium is a common condition in older patients and can be confused with dementia in its acute stages. Other types of dementia, such as vascular dementia, share cognitive and behavioral symptoms with Alzheimer's disease, and thus may be difficult to distinguish from Alzheimer's disease. The cognitive symptoms of early Alzheimer's disease and those associated with normal age-related decline also may be similar. Finally, cognitive deficits are prominent in both late-life depression and schizophrenia. While the severity of deficits is less in these disorders than that in later stages of dementia, distinctions may be difficult if the dementia is early in its course.

A further challenge in the identification of Alzheimer's disease is the widespread societal view of "senility" as a natural developmental stage. Early symptoms of cognitive decline may be excused away or ignored by family members and the patient, making early detection and treatment difficult. The clinical diagnosis of Alzheimer's disease relies on an accurate history of the patient's symptoms and rate of decline. Such information is often impossible to obtain from the patient due to the prominence of memory dysfunction. Family members or other informants are usually helpful, but their ability to provide useful information sometimes is hampered by denial or lack of knowledge about signs and symptoms of the disorder.

With diagnosis so challenging, Alzheimer's disease and other dementias are currently underrecognized, especially in primary care settings, where most older patients seek care. In a study in the United Kingdom, O'Connor and colleagues found that general practitioners recognized only 58 percent of patients identified by research psychiatrists using a structured diagnostic interview (O'Connor et al., 1988). Similarly, in a study conducted in the United States, Callahan and colleagues found that only 3.2 percent of patients with mild cognitive impairment were recognized by general practitioners as having intellectual compromise, and only 23.5 percent of those with moderate to severe dementia were identified as having a dementia syndrome (Callahan et al., 1995). The reasons for primary care provider difficulty with diagnosis are speculated to include lack of knowledge or skills, misdiagnosis of depression as dementia, lack of time, and lack of adequate referrals to specialty mental health care.

The urgency of addressing obstacles to recognition and accurate diagnosis is underscored by promising studies that point to the pronounced clinical advantages of early detection. Therapies that slow the progression of Alzheimer's disease or improve existing symptoms are likely to be most effective if given early in the clinical course. Recognition of early Alzheimer's disease, in addition to facilitating pharmacotherapy, has a variety of other benefits that improve the plight of patients and their families. Direct benefits to patients include improved diagnosis of other potentially reversible causes of dementia, such as hypothyroidism, and identification of sources of Alzheimer's disease's excess disability such as depression and anxiety that can be targeted with nonpharmacological interventions. Family members benefit from early detection by having more time to adjust and plan for the future and by having the opportunity for greater patient input into decisions regarding advanced directives while the patient is still at a mild stage of the illness (Cummings & Jeste, 1999).

Diagnosis of Alzheimer's disease would be greatly improved by the discovery of a biological marker that correlates strongly with neuropathological signs of

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Alzheimer's disease, reflects the severity of pathological changes in Alzheimer's disease, and precedes the appearance of clinical symptomatology. Ideally, such a marker also would be used to monitor the effectiveness of treatment on the clinical manifestations of Alzheimer's disease, would show specificity for Alzheimer's disease with few false positives (i.e., a diagnosis of Alzheimer's disease in someone who does not have the disease), and would be convenient and inexpensive enough to justify wide use, including screening (Cummings & Jeste, 1999). Discovery of such a marker is clearly a research priority.

Behavioral Symptoms

Alzheimer's disease is associated with a range of symptoms evident in cognition and other behaviors; these include, most notably, psychosis, depression, agitation, and wandering. Other behavioral symptoms of Alzheimer's disease include insomnia; incontinence; catastrophic verbal, emotional, or physical outbursts; sexual disorders; and weight loss. Behavioral symptoms, however, are not required for diagnosis. While behavioral symptoms have received less attention than cognitive symptoms, they have serious ramifications: patient and caregiver distress, premature institutionalization, and significant compromise of the quality of life of patients and their families (Rabins et al., 1982; Ferris et al., 1987; Finkel et al., 1996; Kaufer et al., 1998). Alzheimer's disease, especially behavioral symptoms, appears to place patients at risk for abuse by caregivers (Coyne et al., 1993).

Behavioral symptoms occur at some point during the disease with high frequencies: 30 to 50 percent of individuals with Alzheimer's disease experience delusions, 10 to 25 percent have hallucinations, and 40 to 50 percent have symptoms of depression (Mega et al., 1996; Cummings et al., 1998b). Patients with psychotic disorders have greater cognitive impairment, more rapidly progressive dementia, and greater frontal and temporal dysfunction on functional brain imaging (Jeste et al., 1992; Sultzer et al., 1995). Patients with psychotic illness also exhibit more agitation, depression, wandering, anger, personality change, family or marital problems, and lack of self-care (Rockwell et al., 1994). Depression in patients with Alzheimer's disease accelerates loss of functioning in everyday activities (Ritchie et al., 1998). Even modest reduction in behavioral symptoms can produce substantial improvements in functioning and quality of life.

Course

Patients with Alzheimer's disease experience a gradual decline in functioning throughout the course of their illness. Typically, a loss of 4 points per year on the Mini Mental Status Exam is detected, but there is a great deal of heterogeneity in the rate of decline (Olichney et al., 1998). Memory dysfunction is not only the most prominent deficit in dementia but also is the most likely presenting symptom. Deficits in language and executive functioning, while common in the disorder, tend to manifest later in its course (Locascio et al., 1995). Depression is prevalent in the early stages of dementia and appears to recede with functional decline (Locascio et al., 1995). Although this may reflect decreasing awareness of depression by the patient, it also could reflect inadequate detection of depression by health professionals. Behavioral symptoms, such as agitation, seem to be more prevalent in the later stages of Alzheimer's disease (Patterson & Bolger, 1994); however, psychosis has been observed in patients with varying levels of severity (Borson & Raskind, 1997). The duration of illness, from onset of symptoms to death, averages 8 to 10 years (DSM-IV).

Prevalence and Incidence

Alzheimer's disease is a prominent disorder of old age: 8 to 15 percent of people over age 65 have Alzheimer's disease (Ritchie & Kildea, 1995). The prevalence of dementia (most of which is accounted for by Alzheimer's disease) nearly doubles with every 5 years of age after age 60 (Jorm et al., 1987). Although more women than men have Alzheimer's disease (that is, the *prevalence* of the disease appears to be higher among women), this may reflect women's longer life spans, because studies do not show marked gender differences in *incidence* rates (Lebowitz et al., 1998). Incidence studies also reveal age-related increases in Alzheimer's disease (Breteler et al., 1992; Paykel et al., 1994; Hebert et al., 1995; Johansson & Zarit, 1995; Aevarsson & Skoog, 1996). One percent of those age 60 to 64 are affected with dementia; 2 percent of those age 65 to 69; 4 percent of those age 70 to 74; 8 percent of those 75 to 79; 16 percent of those age 80 to 84; and 30 to 45 percent of those age 85 and older (Jorm et al., 1987; Evans et al., 1989).

The "graying of America" is likely to result in an increase in the number of individuals with Alzheimer's disease, yet shifts in the composition of the affected population also are anticipated. Increased education is correlated with a lower frequency of Alzheimer's disease (Hill et al., 1993; Katzman, 1993; Stern et al., 1994), and future cohorts are expected to have attained greater levels of education. For example, the portion of those currently 75 years of age and older—those most vulnerable to Alzheimer's disease—with at least a high school education is 58.7 percent. Of those currently age 60 to 64 who will enter the period of maximum vulnerability by the year 2010, 75.5 percent have at least a high school education. A higher educational level among the at-risk cohort may delay the onset of Alzheimer's disease and thereby decrease the overall frequency of Alzheimer's disease (by decreasing the number of individuals who live long enough to enter the period of maximum vulnerability). However, this trend may be counterbalanced or overtaken by greater longevity and longer survival of affected individuals. Specifically, improvements in general health and health care may lengthen the survival of dementia patients, increasing the number of severely affected patients and raising their level of medical comorbidity. Similarly, through dissemination of information to patients and clinicians, better detection, especially of early-stage patients, is expected. Increased use of putative protective agents, such as vitamin E, also may increase the number of patients in the middle phases of the illness (Cummings & Jeste, 1999).

Cost

The growing number of patients with Alzheimer's disease is likely to have serious public health and economic consequences. Direct and indirect costs for medical and long-term care, home care, and loss of productivity for caregivers are estimated at nearly $100 billion each year (Ernst & Hay, 1994; National Institute on Aging, 1996). This economic burden is borne mostly by families of patients with Alzheimer's disease, although a significant portion of the direct costs is covered by Medicare, Medicaid, and private insurance companies. Costs are especially high among patients with behavioral symptoms, who often require earlier or more frequent institutionalization (Ferris et al., 1987).

Etiology of Alzheimer's Disease

Biological Factors

The etiology of Alzheimer's disease is still incompletely understood yet is thought to entail a complex combination of genetic and environmental factors. Genetic factors appear to play a significant role in the pathogenesis of Alzheimer's disease. In the familial form, Alzheimer's disease is caused by mutations in chromosomes 21, 14, and 1 and is transmitted in an autosomal dominant mode. Each of these mutations appears to result in overproduction of the protein found in neuritic plaques, β-amyloid. Onset of the familial form is usually early, but the course and nature of the disorder appear to be influenced by environmental factors (Cummings et al., 1998b). However, the familial form accounts for only a small proportion of cases of Alzheimer's disease (less than 5 percent) (Cummings et al., 1998b).

Approximately 50 percent of individuals with a family history of Alzheimer's disease, if followed into their 80s and 90s, develop the disorder (Mohs et al., 1987). Certain genotypes (the pattern of genetic inheritance in an individual) appear to confer risk for the more common late-onset form of Alzheimer's disease. For example, the ApoE-e4 allele[4] on chromosome 19, which increases the deposition of β-amyloid, has been shown to increase risk for developing Alzheimer's disease (Corder et al., 1993).

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[4] An allele is a variant form of a gene.

Other possible candidate genes are under study (Kang et al., 1997).

Other biological risk factors for the development of Alzheimer's disease include aging and cognitive capacities (Cummings et al., 1998b). The mechanisms by which these traits confer increased risk have not yet been fully determined; however, several neurobiologic changes related to normal aging of the brain may play a role in the increased risk for Alzheimer's disease with increasing age. These include neuron and synaptic loss, decreased dendritic span, decreased size and density of neurons in the nucleus basalis of Meynert, and lower cortical acetylcholine levels (Cummings et al., 1998b). These findings, as well as extrapolations from the prevalence and incidence curves for Alzheimer's disease, have led some to suggest that most individuals would eventually develop Alzheimer's disease if the human life span was extended (for example, to age 120).

Protective Factors

Several protective factors that delay the onset of Alzheimer's disease have been identified. Genetic endowment with the ApoE-e2 allele decreases the risk for Alzheimer's disease (Duara et al., 1996), although the mechanism of action is not yet fully understood. Higher educational level also is related to delayed onset of Alzheimer's disease (Stern et al., 1994; Callahan et al., 1996a). The use of certain medications, such as nonsteroidal anti-inflammatory drugs (Andersen et al., 1995; McGeer et al., 1996) and estrogen replacement therapy (Paganini-Hill & Henderson, 1994), may delay onset of the disorder. Vitamin E and the drug selegiline (also known as deprenyl) appear to delay the occurrence of important milestones in the course of Alzheimer's disease, including nursing home placement, severe functional impairments even as the disease progresses, and death (Sano et al., 1997).

The mechanism of action of these protective agents is not fully understood but is thought to counter the deleterious action of oxidative stress (via antioxidants such as vitamin E or estrogen) (Behl et al., 1995) or the action of inflammatory mediators associated with plaque formation (via anti-inflammatories) (Mrak et al., 1995).

Histopathology

The pathophysiology of Alzheimer's disease appears to be linked to the histopathologic changes in Alzheimer's disease, which include neuritic plaques, neurofibrillary tangles, synaptic loss, hippocampal granulovacuolar degeneration, and amyloid angiopathy. Most of the genetic and epigenetic risk factors have been related in some way to β-amyloid. Thus, the generation of β-amyloid peptide is increasingly regarded as the central pathological event in Alzheimer's disease (Cummings et al., 1998b; Hardy & Higgins, 1992).

Effective intervention for Alzheimer's disease may involve interfering with the multiple steps within the putative Alzheimer's disease pathogenetic cascade. Targets of intervention include reducing β-amyloid generation from the amyloid precursor protein, decreasing β-amyloid aggregation and formation of beta-pleated sheets, and interfering with amyloid-related neurotoxicity. In addition, therapies could involve interruption of neuronal cell death, inhibition of the inflammatory response occurring in neuritic plaques, use of growth factors and hormonal therapies, and replenishment of deficient neurotransmitters. Because complete blockade of steps within the β-amyloid cascade may interfere with normal cerebral metabolic processes, efficacious interventions could involve partial interruptions (Cummings & Jeste, 1999).

Researchers in the molecular neuroscience of Alzheimer's disease are exploring a number of important aspects of pathophysiology and etiology. As understanding of mechanisms of cell death and neuronal degeneration increases, new opportunities for the development of therapeutics are expected to emerge (National Institute on Aging, 1996).

Role of Acetylcholine

Loss of the neurotransmitter acetylcholine also is thought to play an instrumental role in the pathogenesis of Alzheimer's disease. Postmortem studies of Alzheimer's disease consistently have demonstrated the loss of basal forebrain and cortical cholinergic neurons and the depletion of choline acetyltransferase, the enzyme responsible for acetylcholine synthesis (Mesulam, 1996). The degree of this central cholinergic deficit is correlated with the severity of dementia, which has led to the "cholinergic hypothesis" of cognitive deficits in Alzheimer's disease. This hypothesis has led, in turn, to promising clinical interventions discussed below. It should be emphasized, however, that acetylcholine is not necessarily the only neurotransmitter involved in Alzheimer's disease; research has not ruled out the contributions of other substances in pathogenesis of the disease.

Pharmacological Treatment of Alzheimer's Disease

Pharmacological treatment of Alzheimer's disease is a promising new focus for interventions. A delay in onset of Alzheimer's disease for 5 years might reduce the prevalence of Alzheimer's disease by as much as one-half (Breitner, 1991). In other words, to influence the prevalence of Alzheimer's disease, it may be necessary only to delay the onset of the disease to the point where mortality from other sources supersedes the incidence of Alzheimer's disease. Thus, a central goal in Alzheimer's disease treatment research is the identification of agents that prevent the occurrence, defer the onset, slow the progression, or improve the symptoms of Alzheimer's disease. Progress has been made in this research arena, with several agents showing beneficial effects in Alzheimer's disease.

Acetylcholinesterase Inhibitors

Recent attempts to treat Alzheimer's disease have focused on enhancing acetylcholine function, using either cholinergic receptor agonists (e.g., nicotine) or, most commonly, using acetylcholinesterase (AChE) inhibitors (e.g., physostigmine, velnacrine, tacrine, donepezil, or metrifonate) to increase the availability of acetylcholine in the synaptic cleft. Such treatments have generally been beneficial in ameliorating global cognitive dysfunction and, more specifically, are most effective in improving attention (Norberg, 1996; Lawrence & Sahakian, 1998). Amelioration of learning and memory impairments, the most prominent cognitive deficits in Alzheimer's disease, have been found less consistently (Lawrence & Sahakian, 1998), although some studies have shown improvements (Thal, 1996). It has been argued that failure of AChE inhibitors and nicotine to improve learning and memory may be due to high levels of neurodegeneration in the medial temporal lobe (Lawrence & Sahakian, 1998). Neuronal degeneration in this region of the brain leaves neurons impervious to the benefits of some types of replacement therapy. Detailed neuropsychological studies of the effects of the newer cognitive enhancers, donepezil and metrifonate (an experimental drug), have not yet been published, but global cognitive functioning appears to be improved with both compounds (Cummings et al., 1998a; Rogers et al., 1998). Treatment with these AChE inhibitors also appears to benefit noncognitive symptoms in Alzheimer's disease, such as delusions (Raskind et al., 1997) and behavioral symptoms (Kaufer et al., 1996; Morris et al., 1998).

Treatment of Behavioral Symptoms

The behavioral symptoms of Alzheimer's disease have received less therapeutic attention than cognitive symptoms. Few double-blind, placebo-controlled studies of medications for behavioral symptoms of Alzheimer's disease have been performed. For the most part, behavioral symptoms have been treated with medications developed for primary psychiatric symptoms. The emergence of new antipsychotic and antidepressant medications requires that these agents be studied specifically for Alzheimer's disease. The observation that cholinergic agents used to enhance cognition in Alzheimer's disease may have beneficial behavioral effects also needs further exploration (Kaufer et al., 1996; Bodick et al., 1997; Raskind et al., 1997).

One area that has been studied is the treatment of depression in Alzheimer's disease. Treatment with the antidepressants paroxetine and imipramine has been shown to be effective in depressed Alzheimer's disease patients (Reifler et al., 1989; Katona et al., 1998). Treatment may not only be effective for relieving depressive symptoms but also for its potential to improve functional ability (Pearson et al., 1989; Ritchie et al., 1998).

Several challenges are encountered with the pharmacological treatment of Alzheimer's disease. First, because of the cognitive deficits that are the hallmark of dementia, caregiver assistance is crucial for compliance with pharmacotherapy regimens. Second, although the current pharmacotherapies are likely to be most useful if administered early in the course of the disorder, early detection of Alzheimer's disease is encumbered by the lack of a verified biological or biobehavioral marker. Third, little is currently known about the optimal duration of treatment with pharmacotherapies.

Psychosocial Treatment of Alzheimer's Disease Patients and Caregivers

Psychosocial interventions are extremely important in Alzheimer's disease. Although there has been some research on preserving cognition, most research has focused on treating patients' behavioral symptoms and relieving caregiver burden. Support for caregivers is crucial because caregivers of older patients are at risk for depression, anxiety, and somatic problems (Light & Lebowitz, 1991). Psychosocial interventions targeted either at patients or family caregivers can improve outcomes for patients and caregivers alike.

Psychosocial techniques developed for use in patients with cognitive impairment may be helpful in Alzheimer's disease. Strengthening ways to deal with cognitive losses may reduce functional limitations for patients with the early stages of Alzheimer's disease, before multiple brain systems become compromised. For example, training in the use of memory aids, such as mnemonics, computerized recall devices, or copious use of notetaking, may assist patients with mild dementia. While initial research on the use of cognitive rehabilitation in dementia is promising, further studies are needed (Pliskin et al., 1996).

Of the behavioral symptoms experienced by patients with Alzheimer's disease, depression and anxiety occur most frequently during the early stages of dementing disorders, whereas psychotic symptoms and aggressive behavior occur during later stages (Alexopoulos & Abrams, 1991; Devanand et al., 1997). Early evidence suggested that cognitive and behavioral therapies are beneficial in treating depressed older patients with dementia (Teri & Gallagher-Thompson, 1991; Teri & Uomoto, 1991). Cognitive therapy, seen as more promising for the early stages of dementia, strives to help patients cope with depression by reducing cognitive distortions and by fostering more adaptive perceptions. Behavioral therapy, seen as more promising for more moderately or severely affected adults with dementia, targets family caregivers directly—and patients indirectly—by helping caregivers identify, plan, and increase pleasant activities for the patient, such as taking a walk, designed to improve their mood (Teri & Gallagher-Thompson, 1991).

Further affirmation for behavioral therapy for depression of patients with Alzheimer's disease recently was provided by a controlled clinical trial. The trial compared two types of behavioral therapy with a typical care condition and a waiting list control. One of the behavioral therapies targeted family caregivers to help them increase pleasant events for the patients, while the other gave caregivers more latitude in choosing which behavioral problem-solving strategies to deal with patients' depression. Both behavioral therapies led to significant improvement in patients' depressive symptoms. Moreover, the caregivers also showed significant improvement in their own depressive symptoms (Teri et al., 1997).

For alleviating caregiver and family distress, a broad array of psychosocial interventions was assessed in a meta-analysis of 18 studies (Knight et al., 1993). The interventions included psychoeducation, support, cognitive-behavioral techniques, self-help, and respite care. Individual and respite programs were found moderately effective at reducing caregiver burden and dysphoria, but group interventions were only marginally effective. Subsequent research buttressed the utility of adult day care in reducing caregivers' stress and depression and in enhancing their well-being (Zarit et al., 1998). Beyond direct benefits to caregivers, support interventions also have benefited patients and have saved resources. For example, a psychosocial intervention—individual and family counseling plus support group participation—aimed at caregiving spouses was shown to delay institutionalization of patients with dementia by almost a year in a randomized trial (Mittelman et al., 1993, 1996). Targeted behavioral techniques also improved the quality of caregivers' sleep (McCurry et al., 1996), whereas psychoeducation and family support appeared to promote better patient management (Zarit et al., 1985).

The virtues of psychosocial interventions also extend to patients with Alzheimer's disease in nursing homes. Until the late 1980s, nursing homes employed restraints and sedatives and other medications to control behavioral symptoms in patients with dementia. But the untoward consequences, in terms of injuries from physical restraints and increased patient disorientation, led to nursing home reform practices required by the Federal Nursing Home Reform Act of the Omnibus Budget Reconciliation Act of 1987 (Cohen & Cairl, 1996). In the past few years, a range of behavioral interventions for nursing home staff has been shown to be effective in improving behavioral symptoms of Alzheimer's disease, such as incontinence (Burgio et al., 1990; Schnelle et al., 1995), dressing problems (Beck et al., 1997), and verbal agitation (Burgio et al., 1996; Cohen-Mansfield & Werner, 1997). A major problem is that interventions are not maintained or implemented correctly by nursing home staff (Schnelle et al., 1998). New approaches seek to teach and maintain behavior management skills of nursing home assistants through a formal staff management system (Barinaga, 1998; Stevens et al., 1998).

Other Mental Disorders in Older Adults

Anxiety Disorders

Prevalence of Anxiety

Anxiety symptoms and syndromes are important but understudied conditions in older adults. Overall, community-based prevalence estimates indicate that about 11.4 percent of adults aged 55 years and older meet criteria for an anxiety disorder in 1 year (Flint, 1994; Table 5-1). Phobic anxiety disorders are among the most common mental disturbances in late life according to the ECA study (Table 5-1). Prevalence studies of panic disorder (0.5 percent) and obsessive-compulsive disorder (1.5 percent) in older samples reveal low rates (Table 5-1) (Copeland et al., 1987a; Copeland et al., 1987b; Bland et al., 1988; Lindesay et al., 1989). Although the National Comorbidity Survey did not cover this age range, and the ECA did not include this disorder, other studies showed a prevalence of generalized anxiety disorder in older adults ranging from 1.1 percent to 17.3 percent higher than that reported for panic disorder or obsessive-compulsive disorder (Copeland et al., 1987a; Skoog, 1993). Worry or "nervous tension," rather than specific anxiety syndromes may be more important in older people. Anxiety symptoms that do not fulfill the criteria for specific syndromes are reported in up to 17 percent of older men and 21 percent of older women (Himmelfarb & Murrell, 1984).

In addition, some disorders that have received less study in older adults may become more important in the near future. For example, post-traumatic stress disorder (PTSD) is expected to assume increasing importance as Vietnam veterans age. At 19 years after combat exposure, this cohort of veterans has been found to have a PTSD prevalence of 15 percent (cited in McFarlane & Yehuda, 1996). As affected patients age, there is a continuing need for services. In addition, research has shown that PTSD can manifest for the first time long after the traumatic event (Aarts & Op den Velde, 1996), raising the specter that even more patients will be identified in the future.

Treatment of Anxiety

The effectiveness of benzodiazepines in reducing *acute* anxiety has been demonstrated in younger and older patients, and no differences in the effectiveness have been documented among the various benzodiazepines. Some research suggests that benzodiazepines are marginally effective at best in treating *chronic* anxiety in older patients (Smith et al., 1995).

The half-life of certain benzodiazepines and their metabolites may be significantly extended in older patients (particularly for the compounds with long half-life). If taken over extended periods, even short-acting benzodiazepines tend to accumulate in older individuals. Thus, it is generally recommended that any use of benzodiazepines be limited to discrete periods (less than 6 months) and that long-acting compounds be avoided in this population. On the other hand, use of short-acting compounds may predispose older patients to withdrawal symptoms (Salzman, 1991).

Side effects of benzodiazepines may include drowsiness, fatigue, psychomotor impairment, memory or other cognitive impairment, confusion, paradoxical reactions, depression, respiratory problems, abuse or dependence problems, and withdrawal reactions. Benzodiazepine toxicity in older patients includes sedation, cerebellar impairment (manifested by ataxia, dysarthria, incoordination, or unsteadiness), cognitive impairment, and psychomotor impairment (Salzman, 1991). Psychomotor impairment from benzodiazepines can have severe consequences, leading to impaired driver skills and motor vehicle crashes (Barbone et al., 1998) and falls (Caramel et al., 1998).

Buspirone is an anxiolytic (antianxiety) agent that is chemically and pharmacologically distinct from benzodiazepines. Controlled studies with younger patients suggest that the efficacy of buspirone is comparable to that of the benzodiazepines. It also has proven effective in studies of older patients (Napoliello, 1986; Robinson et al., 1988; Bohm et al., 1990). On the other hand, buspirone may require up to 4 weeks to take effect, so initial augmentation with another antianxiety medication may be necessary for some acutely anxious patients (Sheikh, 1994). Significant adverse reactions to buspirone are found in 20 to 30 percent of anxious older patients (Napoliello, 1986; Robinson et al., 1988). The most frequent side effects include gastrointestinal symptoms, dizziness, headache, sleep disturbance, nausea/vomiting, uneasiness, fatigue, and diarrhea. Still, buspirone may be less sedating than benzodiazepines (Salzman, 1991; Seidel et al., 1995).

Although the efficacy of antidepressants for the treatment of anxiety disorders in late life has not been studied, current patterns of practice are informed by the efficacy literature in adults in midlife (see Chapter 4).

Schizophrenia in Late Life

Although schizophrenia is commonly thought of as an illness of young adulthood, it can both extend into and first appear in later life. Diagnostic criteria for schizophrenia are the same across the life span, and DSM-IV places no restrictions on age of onset for a diagnosis to be made. Symptoms include delusions, hallucinations, disorganized speech, disorganized or catatonic behavior (the so-called "positive" symptoms), as well as affective flattening, alogia, or avolition[5] (the so-called "negative" symptoms). Symptoms must cause significant social or occupational dysfunction, must not be accompanied by prominent mood symptoms, and must not be uniquely associated with substance use.

Prevalence and Cost

One-year prevalence of schizophrenia among those 65 years or older is reportedly only around 0.6 percent, about one-half the 1-year prevalence of the 1.3 percent that is estimated for the population aged 18 to 54 (Tables 5-1 and 4-1).

The economic burden of late-life schizophrenia is high. A study using records from a large California county found the mean cost of mental health service for schizophrenia to be significantly higher than that for other mental disorders (Cuffel et al., 1996); the mean expenditure among the oldest patients with schizophrenia (> 74 years old) was comparable to that among the youngest patients (age 18 to 29). While long-term studies have shown that use of nursing homes, state hospitals, and general hospital care by patients with all mental disorder diagnoses has declined in recent decades, the rate of decline is lower for older patients with schizophrenia (Kramer et al., 1973; Redick et al., 1977). The high cost of these settings contributes to the greater economic burden associated with late-life schizophrenia.

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[5] Alogia refers to poverty of speech, and avolition refers to lack of goal-directed behavior.

Late-Onset Schizophrenia

Studies have compared patients with late onset (age at onset 45 years or older) and similarly aged patients with earlier onset of schizophrenia (Jeste et al., 1997); both were very similar in terms of genetic risk, clinical presentation, treatment response, and course.

Among key differences between the groups, patients with late-onset schizophrenia were more likely to be women in whom paranoia was a predominant feature of the illness. Patients with late-onset schizophrenia had less impairment in the specific neurocognitive areas of learning and abstraction/cognitive flexibility and required lower doses of neuroleptic medications for management of their psychotic symptoms. These and other differences between patients with early- and late-onset illness suggest that there might be neurobiologic differences mediating the onset of symptoms (DeLisi, 1992; Jeste et al., in press).

Course and Recovery

The original conception of "dementia praecox," the early term for schizophrenia, emphasized progressive decline (Kraepelin, 1971); however, it now appears that Kraepelin's picture captures the outcome for a small percentage of patients, while one-half to two-thirds significantly improve or recover with treatment and psychosocial rehabilitation (Chapter 4). Although the rates of full remission remain unclear, some patients with schizophrenia demonstrate remarkable recovery after many years of chronic dysfunction (Nasar, 1998). Research suggests that a factor in better long-term outcome is early intervention with antipsychotic medications during a patient's first psychotic episode (See Chapter 4).

A recent cross-sectional study that compared middle-aged with older patients, all of whom lived in community settings, found some similarities and differences (Eyler-Zorrilla et al., 1999). The older patients experienced less severe symptoms overall and were on lower daily doses of neuroleptics than middle-aged patients who were similar in demographic, clinical, functional, and broad cognitive measures. In addition, positive symptoms were less prominent (or equivalent) in the older group, depending on the measure used. Negative symptoms were more prominent (or equivalent) in the older group, and older patients scored more poorly on severity of dyskinesia. Older patients were impaired relative to middle-aged ones on two measures of global cognitive function. This finding, however, appeared to reflect a normal degree of decline from an impaired baseline, as the degree of change in cognitive function with age in the patient group was equivalent to that seen in the comparison group.

A recent study used the Direct Assessment of Functional Status scale (DAFS) (Loewenstein et al., 1989) to compare the everyday living skills of middle-aged and older adults with schizophrenia with those of people without schizophrenia of similar ages (Klapow et al., 1997). The patients exhibited significantly more functional limitations than the controls did across most DAFS subscales. In another recent study that used a measure of overall disease impact, the Quality of Well-Being Scale, older outpatients with schizophrenia manifested significantly lower quality of well-being than did comparison subjects, and their scores were slightly worse than those of ambulatory AIDS patients (Patterson et al., 1996).

Thus, while schizophrenia may be less universally deteriorating than previously has been assumed, older patients with the disorder continue nonetheless to exhibit functional deficits that warrant research and clinical attention.

Etiology of Late-Onset Schizophrenia

Recent studies support a neurodevelopmental view of late-onset schizophrenia (Jeste et al., 1997). Equivalent degrees of childhood maladjustment have been found in patients with late-onset schizophrenia and early-onset schizophrenia, for example, suggesting that some liability for the disorder exists early in life. Equivalent degrees of minor physical anomalies in patients with late-onset schizophrenia and early-onset schizophrenia suggest the presence of developmental defects in both groups (Lohr et al., 1997). The presence of a genetic contribution to late-onset and early-onset schizophrenia is evident in increased rates of schizophrenia among first-degree relatives (Rokhlina, 1975; Castle & Howard, 1992; Castle et al., 1997).

If late-onset schizophrenia is neurodevelopmental in origin, an explanation for the delayed onset may be that late-onset schizophrenia is a less severe form of the disorder and, as such, is less likely to manifest early in life. Recent research suggests that in several arenas—for example, neuropsychological impairments in learning, retrieval, abstraction, and semantic memory as well as electroencephalogram abnormalities—the deficits of patients with late-onset schizophrenia are less severe (Heaton et al., 1994; Jeste et al., 1995b; Olichney et al., 1995, 1996; Paulsen et al., 1995, 1996). Also, negative symptoms are less pronounced and neuroleptic doses are lower in patients with late-onset schizophrenia (Jeste et al., 1995b). The etiology and onset of schizophrenia in younger adults often are explained by a diathesis-stress model in which there is a genetic vulnerability in combination with an environmental insult (such as obstetric complications), with onset triggered by maturational changes or life events that stress a developmentally damaged brain (Feinberg, 1983; Weinberger, 1987; Wyatt, 1996). Under this multiple insult model, patients with late-onset schizophrenia may have had fewer insults and thus have a delayed onset. An alternative or complementary explanation for the delayed onset in late-onset schizophrenia is the possibility that these patients possess protective features that cushion the blow of any additional insults. The preponderance of women among patients with late-onset schizophrenia has fueled hypotheses that estrogen plays a protective role.

The view of late-onset schizophrenia as a less severe form of schizophrenia, in which the delayed onset results from fewer detrimental insults or the presence of protective factors, suggests a continuous relationship between age at onset and severity of liability. An alternative view is that late-onset schizophrenia is a distinct neurobiological subtype of schizophrenia. The preponderance of women and of paranoid subtype patients seen in late-onset schizophrenia supports this view. These two etiologic theories of late-onset schizophrenia call for further research.

Treatment of Schizophrenia in Late Life

Pharmacological treatment of schizophrenia in late life presents some unique challenges. Conventional neuroleptic agents, such as haloperidol, have proven effective in managing the "positive symptoms" (such as delusions and hallucinations) of many older patients, but these medications have a high risk of potentially disabling and persistent side effects, such as tardive dyskinesia (Jeste et al., in press). The cumulative annual incidence of tardive dyskinesia among older outpatients (29 percent) treated with relatively low daily doses of conventional antipsychotic medications is higher than that reported in younger adults (Jeste et al., in press).

Recent years have witnessed promising advances in the management of schizophrenia. Studies with mostly younger schizophrenia patients suggest that the newer "atypical" antipsychotics, such as clozapine, risperidone, olanzapine, and quetiapine, may be effective in treating those patients previously unresponsive to traditional neuroleptics. They also are associated with a lower risk of extrapyramidal symptoms and tardive dyskinesia (Jeste et al., in press). Moreover, the newer medications may be more effective in treating negative symptoms and may even yield partial improvement in certain neurocognitive deficits associated with this disorder (Green et al., 1997).

The foremost barriers to the widespread use of atypical antipsychotic medications in older adults are (1) the lack of large-scale studies to demonstrate the effectiveness and safety of these medications in older patients with multiple medical conditions, and (2) the higher cost of these medications relative to traditional neuroleptics (Thomas & Lewis, 1998).

Alcohol and Substance Use Disorders in Older Adults

Older people are not immune to the problems associated with improper use of alcohol and drugs, but as a rule, *misuse* of alcohol and prescription medications appears to be a more common problem among older adults than *abuse* of illicit drugs. Still, because few studies of the incidence and prevalence of substance abuse have focused on older adults—and because those few were beset by methodological problems—the popular perception may be misleading.

A persistent research problem has been that diagnostic criteria for substance abuse were developed and validated on young and middle-aged adults. For example, DSM-IV criteria include increased tolerance to the effects of the substance, which results in increased consumption over time; yet, changes in pharmacokinetics and physiology may alter drug tolerance in older adults. Decreased tolerance to alcohol among older individuals may lead to decreased consumption of alcohol with no apparent reduction in intoxication. Criteria that relate to the impact of drug use on typical tasks of young and middle adulthood, such as school and work performance or child rearing, may be largely irrelevant to older adults, who often live alone and are retired. Thus, abuse and dependence among older adults may be underestimated (Ellor & Kurz, 1982; Miller et al., 1991; King et al., 1994).

Epidemiology

Alcohol Abuse and Dependence

The prevalence of heavy drinking (12 to 21 drinks per week) in older adults is estimated at 3 to 9 percent (Liberto et al., 1992). One-month prevalence estimates of alcohol abuse and dependence in this group are much lower, ranging from 0.9 percent (Regier et al., 1988) to 2.2 percent (Bailey et al., 1965). Alcohol abuse and dependence are approximately four times more common among men than women (1.2 percent vs. 0.3 percent) ages 65 and older (Grant et al., 1994). Although lifetime prevalence rates for alcoholism are higher for white men and women between ages 18 and 29, African American men and women have higher rates among those 65 years and older. For Hispanics, men had rates between those of whites and African Americans. Hispanic females had a much lower rate than that for whites and African Americans (Helzer et al., 1991). Longitudinal studies suggest variously that alcohol consumption decreases with age (Temple & Leino, 1989; Adams et al., 1990), remains stable (Ekerdt et al., 1989), or increases (Gordon & Kannel, 1983), but it is anticipated that alcohol abuse or dependence will increase as the baby boomers age, since that cohort has a greater history of alcohol consumption than current cohorts of older adults (Reid & Anderson, 1997).

Misuse of Prescription and Over-the-Counter Medications

Older persons use prescription drugs approximately three times as frequently as the general population (Special Committee on Aging, 1987), and the use of over-the-counter medications by this group is even more extensive (Kofoed, 1984). Annual estimated expenditures on prescription drugs by older adults in the United States are $15 billion annually, a fourfold greater per capita expenditure on medications compared with that of younger individuals (Anderson et al., 1993; Jeste & Palmer, 1998). Not surprisingly, substance abuse problems in older adults frequently may result from the misuse—that is, underuse, overuse, or erratic use—of such medications; such patterns of use may be due partly to difficulties older individuals have with following and reading prescriptions (Devor et al., 1994). In its extreme form, such misuse of drugs may become drug abuse (Ellor & Kurz, 1982; DSM-IV).

Research studies that have relied on medical records review show consistently that alcohol abuse and dependence are significantly more common than other forms of substance abuse and dependence (Finlayson & Davis, 1994; Moos et al., 1994). Yet prescription drug dependence is not uncommon and, as Finlayson and Davis (1994) found, the greatest risk factor for abuse of prescription medication was being female. This finding is supported by other studies showing that older women are more likely than men to visit physicians and to be prescribed psychoactive drugs (Cafferata et al., 1983; Baum et al., 1984; Mossey & Shapiro, 1985; Adams et al., 1990). In contrast, an analysis of data from the National Household Survey on Drug Abuse concluded that older men were more likely than women to report use of sedatives, tranquilizers, and stimulants (Robins & Clayton, 1989). Older adults of both sexes are at risk for analgesic abuse, which can culminate in various nephropathies (Elseviers & De Broe, 1998).

Benzodiazepine use represents an area of particular concern for older adults given the frequency with which these medications are prescribed at inappropriately high doses (Shorr et al., 1990) and for excessive periods of time. A national survey of approximately 3,000 community-dwelling persons found that older persons were overrepresented among the 1.6 percent who had taken benzodiazepines daily for 1 year or longer (71 percent > 50 years; 33 percent > 65 years of age) (Mellinger et al., 1984). Benzodiazepine users were more likely to be older, white, female, less educated, separated/divorced, to have experienced increased stressful life events, and to have a psychiatric diagnosis (Swartz et al., 1991).

Illicit Drug Abuse and Dependence

In contrast to alcohol and licit medications, older adults infrequently use illicit drugs. Less than 0.1 percent of older individuals in the Epidemiologic Catchment Area study met DSM-III (American Psychiatric Association, 1980) criteria for drug abuse/dependence during the previous month (Regier et al., 1988). This compared with a 1-month prevalence rate of 3.5 percent among 18- to 24-year-olds. ECA data further suggest a lifetime prevalence of illegal drug use of 1.6 percent for persons older than 65 years (Anthony & Helzer, 1991).

The development of addiction to illict drugs after young adulthood is rare, while mortality is high (Atkinson et al., 1992). For example, over 27 percent of heroin addicts died during a 24-year period (Hser et al., 1993), and 5.6 percent of deaths associated with heroin or morphine use were among persons older than 55 (National Institute on Drug Abuse, 1992).

As is projected to occur with trends in alcohol consumption, the low prevalence of older adults' drug use and abuse in the late 1990s may change as the baby boomers age. Annual "snapshot" data extrapolated from the National Household Survey on Drug Abuse, which has been conducted since 1971, afford a glimpse of trends. Patterson and Jeste (1999) recently compared prevalence estimates of those born during the baby boom with an older (> 35 years) non-baby-boomer cohort. The difference between baby boomers and the previous cohort translated in 1996 into an excess of approximately 1.1 million individuals using drugs. Their excess drug use, combined with their sheer numbers, means that more drug use is expected as this cohort ages, placing greater pressures on treatment programs and other resources.

Projections also suggest that the costs of alcohol and substance abuse are likely to rise in the near future. Across age ranges, drug abuse and alcohol abuse have been estimated to cost over $109.8 billion and $166.5 billion, respectively (Harwood et al., 1998). Although no studies have estimated the annual costs of alcohol and substance abuse among older adults, there is evidence that the presence of drug abuse and dependence greatly increases health care expenditures among individuals with comorbid medical disorders. For example, in a study of over 3 million Medicare patients who were hospitalized and discharged with a diagnosis of cardiovascular disease, average annual hospital charges were $17,979 for older patients with a concomitant diagnosis of drug dependence and $14,253 for those with a concomitant diagnosis of drug abuse, compared with only $11,387 for older patients with no concomitant drug disorder (Ingster & Cartwright, 1995). In addition, increased expenditures due to the presence of a drug disorder were greatest among older patients who also had a mental disorder.

Course

A longstanding assumption holds that substance abuse declines as people age. Winick (1962) proposed one of the most popular theories to explain apparent decreases in substance abuse, particularly narcotics, with aging. His "maturing out" theory posits that factors associated with aging processes and length of abuse contribute to a decline in the number of older narcotic addicts. These factors include changes in developmental stages and morbidity and mortality associated with use of substances. Consistent with these hypotheses, substance abusers have higher mortality rates compared with age-matched nonabusers (Finney & Moos, 1991; Moos et al., 1994). However, some research contradicts the "maturing out" theory. For example, some studies show that persons who have been addicted for more than 5 years do not become abstinent as they age (Haastrup & Jepsen, 1988; Hser et al., 1993). Also, addicts approaching 50 years of age who were followed for more than 20 years remained involved in criminal activities (Hser et al., 1993). These findings emphasize the need to focus more attention on substance abuse in late life, especially in light of demographic trends.

Treatment of Substance Abuse and Dependence

The treatment of substance abuse and dependence in older adults is similar to that for other adults. Treatment involves a combination of pharmacological and psychosocial interventions, supplemented by family support and participation in self-help groups (Blazer, 1996a).

Pharmacotherapy for substance abuse and dependence in older adults has been targeted mostly at the acute management of withdrawal. When there is significant physical dependence, withdrawal from alcohol can become a life-threatening medical emergency in older adults. The detoxification of older adult patients ideally should be done in the inpatient setting because of the potential medical complications and because withdrawal symptoms in older adults can be prolonged. Benzodiazepines are often used for treatment of withdrawal symptoms. In older adults, the doses required to treat the signs and symptoms of withdrawal are usually one-half to one-third of those required for a younger adult. Short- or intermediate-acting forms usually are preferred.

Pharmacological agents for treatment of substance dependence rarely have been studied in older adults. Disulfiram use in older adults to promote abstinence is not recommended because of the potential for serious cardiovascular complications. Compounds recently proposed for use in treatment of addiction, such as flagyl, deserve further study. A rare controlled clinical trial of substance abuse treatment in older patients recently revealed naltrexone to be effective at preventing relapse with alcohol dependence (Oslin et al., 1997).

Service Delivery

Overview of Services

New perspectives are evolving on the nature of mental health services for older adults and the settings in which they are delivered. Far greater emphasis is being placed on community-based care, which entails care provided in homes, in outpatient settings, and through community organizations. The emphasis on community-based care has been triggered by a convergence of demographic, consumer, and public policy imperatives. In terms of demographics, approximately 95 percent of older persons at a given point in time live in the community rather than in institutions, such as nursing homes (U.S. Department of Health and Human Services, Administration on Aging, and American Association of Retired Persons [U.S.DHHS, AoA & AARP], 1995). Of those living in the community, approximately 30 percent, mostly women, live alone (U.S. DHHS, AoA & AARP, 1995). Most older persons prefer to remain in the community and to maintain their independence. Yet living alone makes them even more reliant on community-based services if they have a mental disorder.

Service delivery also is being shaped by public policy and the emergence of managed care. The escalating costs of institutional care, combined with the recognition of past abuses, stimulated policies to limit nursing home admissions and to shift treatment to the community (Maddox et al., 1996). Mental disorders are leading risk factors for institutionalization (Katz & Parmelee, 1997). Therefore, to keep older people in the community, where they prefer to be, more energies are being marshaled to promote mental health and to prevent or treat mental disorders in the community. In other words, treating mental disorders is seen as a means to stave off costly institutionalization—resulting either from a mental disorder or a comorbid somatic disorder. An untreated mental disorder, for example, can turn a minor medical problem into a life-threatening and costly condition. Problems with forgetting to take medication (e.g., with dementia), developing delusions about medication (e.g., with schizophrenia), or lowering motivation to refill prescriptions (e.g., with depression) can increase the likelihood of having more severe illnesses that demand more intensive and expensive institutional care. Therefore, promotion of mental health and treatment of mental disorders are crucial elements of service delivery.

The delivery of community-based mental health services for older adults faces an enormous challenge. Services for older adults are insufficient and fragmented, often divided between systems of health, mental health, and social services (Gatz & Smyer, 1992; Cohen & Cairl, 1996). Under these three systems, services include medical and psychosocial care, rehabilitation, recreation, housing, education, and other supports. Yet although every community has an Administration on Aging to assist with services for older adults generally, there is no administrative body responsible for integrating the daunting array of services needed specifically for individuals with severe mental illnesses. Similar problems are encountered with coordinating services for children, as discussed in Chapter 3. Local mental health authorities and systems of care have been effective in coordinating care for some groups of adults, but no special administrative mental health entities exist for older adults. The fragmentation of service systems for older people in the United States stands in contrast to the United Kingdom and Ireland, where governmental authorities coordinate their care (Reifler, 1997). Older adults eventually may benefit from the local mental health authorities developing in the United States, but thus far these authorities have been focused on services for other adults. Because of ethnic diversity in the United States, systems of care must also deal with the special needs of older Americans who have limited English proficiency and different cultural backgrounds.

The following section describes the nature and settings in which older people receive mental health services. It concentrates on primary care, adult day centers and other community care settings, and nursing homes. A recurrent theme across these settings is the failure to address mental health needs of older people. Selected issues in financing of services for older adults are discussed briefly at the end of this section, but most of the issues related to financing policy (e.g., Medicare, Medicaid) and managed care are discussed in Chapter 6.

Service Settings and the *New Landscape for Aging*

Demographic, consumer, and public policy imperatives have propelled tremendous growth in the diversity of settings in which older persons simultaneously reside and receive care (Table 5-2). Care is no longer the strict province of home or nursing home. The diversity of home settings in suburban and urban communities extends from naturally occurring retirement communities to continuing care retirement communities to newer types of alternative living arrangements. These settings include congregate or senior housing, senior hotels, foster care, group homes, day centers (where people reside during the day), and others. The diversity of institutional settings includes nursing homes, general hospitals (with and without psychiatric units), psychiatric hospitals, and state mental hospitals, among others. In fact, the range of settings, and the nature of the services provided within each, has blurred the distinction between home and nursing home (Kane, 1995).

Across the range of settings, the duration of care can be short term or long term, depending on patients' needs. The phrase, "long-term care," has come to refer to a *range* of services for people with chronic or degenerative illness or disabilities who require support over a prolonged period of time. In the past, long-term care was synonymous with nursing home care or other forms of institutional care, but the term has come to

Table 5-2. Settings for mental health services for older adults*

Communities	Institutions
Homes	Nursing homes
Group homes	General hospitals with psychiatric units
Retirement communities	General hospitals without psychiatric units
Primary care and general medical sector	State mental hospitals
Outpatient therapy	Veterans Affairs hospitals
Community mental health centers	

*Two other settings (not included in this table) are board and care homes and assisted living facilities. These are residential facilities that serve as a bridge between community and institutional settings and have elements of each.

apply to a full complement of institutional or community-based settings.

Within the continuum of services, one new perspective—conceived as the *landscape for aging*—strives to tailor the environment to the needs of the person through a combined focus on health and residential requirements (Cohen, 1994). Whether at home, in a retirement community, or in a nursing home, this health and home perspective is deemed to be crucial to achieving high quality of life for older adults. Over the past 30 years, improvements in the health side of this perspective have occurred, but the home part has lagged. The challenge is to stimulate an interdisciplinary collaboration between systems of care and consumers.

One important area for an interdisciplinary approach is the extent to which a given setting fosters independent functioning versus dependent functioning, an issue influencing mental health and quality of life. Though certainly not a goal, some settings inadvertently foster dependency rather than independence. Nursing homes and hospitals, for example, are understandably more focused on what individuals *cannot* do, as opposed to what they can do. Yet their major focus on incapacity (the nursing and health focus) runs the risk of overshadowing function and independence (the home and humanities focus). In other settings, the balance between dependence and independence shifts in the other direction, with the risk of nursing and health needs being inadequately addressed. In recent years, the emphasis has been on "aging in place," either at home or in the community, rather than in alternate settings.

The *landscape for aging* is a construct within which to examine the depth and breadth of human experience in later life (Cohen, 1998b). A health and humanities focus across this landscape offers a design for dealing with mental health problems as well as with health promotion to harness human potential. The landscape for aging, with its health and humanities orientation, is a construct designed to stir new thinking in research, practice, and policy. It also defines a clear need for new mental health services' development and delivery, training, research, and policies to address the range of sites, each with its own unique characteristics and growing populations. The service systems, however, have yet to embrace a broader view.

Primary Care

Primary care[b] represents a pivotal setting for the identification and treatment of mental disorders in older people. Many older people prefer to receive mental health treatment in primary care (Unutzer et al., 1997a), a preference bolstered by public financing policies that encourage their increasing reliance on primary, rather than specialty, mental health care (Mechanic, 1998). Primary care offers the potential advantages of proximity, affordability, convenience, and coordination of care for mental and somatic disorders, given that comorbidity is typical.

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[b] Primary care includes services provided by general practitioners, family physicians, general internists, certain specialists designated as primary care physicians (such as pediatricians and obstetrician-gynecologists), nurse practitioners, physician assistants, and other health care professionals. General medical settings include all primary care settings plus all non-mental health specialty care

The potential advantages of primary care, however, have yet to be realized. Diagnosis and treatment of older people's mental disorders in the primary care setting are inadequate. The efficacious treatments described in the depression section of this chapter are not being practiced, particularly not in primary care and other general medical settings. As documented earlier, a significant percentage of older patients with depression are underdiagnosed and undertreated. The concern about inadequate treatment of late-life depression in primary care is magnified by growing enrollment in managed care.

Primary care is generally not well equipped to treat chronic mental disorders such as depression or dementia. It has limited capacity to identify patients with common mental disorders and to provide the proactive followup that is required to retain patients in treatment. To ensure better treatment of late-life depression in primary care, there is heightening awareness of the need for new models for mental health service delivery (Unutzer et al., 1997a). New models of service delivery in primary care include mental health teams, consultation-liaison models,[7] and integration of mental health professionals into primary care (Katon & Gonzales, 1994; Schulberg et al., 1995; Katon et al., 1996, 1997; Stolee et al., 1996; Gask et al., 1997). For example, the intervention developed by Katon and colleagues introduced a structured depression treatment program into the primary care setting. The program included behavioral treatment to inculcate more adaptive coping strategies and counseling to enhance compliance with antidepressant medications. Patients were randomized in a controlled trial comparing this structured depression program with usual care by primary care physicians. The investigators found patients participating in the program to have displayed better medication adherence, better satisfaction with care, and a greater decrease in severity of major depression (Katon et al., 1996).

Models that integrate mental health treatment into primary care, while thus far designed largely for depression, also may have utility for other mental disorders seen in primary care. Nevertheless, primary care is not appropriate for *all* patients with mental disorders. Primary care providers can be guided by a set of recommendations for appropriate referrals to specialty mental health care (American Association for Geriatric Psychiatry, 1997).

Adult Day Centers and Other Community Care Settings

Over the past few decades, adult day centers have developed as an important service delivery approach to providing community-based long-term care. Adult day centers, although heterogeneous in orientation, provide a range of services (usually during standard "9 to 5" business hours), including assessment, social, and recreation services, for adults with chronic and serious disabilities. They represent a form of respite care designed to give caregivers a break from the responsibility of providing care and to enable them to pursue employment. Over the past 30 years, adult day centers have grown in number from fewer than 100 to over 4,000, under the sponsorship of community organizations or residential facilities. A large national demonstration program on adult day centers showed that they can care for a wide spectrum of patients with Alzheimer's disease and related dementias and can achieve financial viability (Reifler et al., 1997; Reifler et al., in press). There also is evidence that adult day centers are cost-effective in terms of delaying institutionalization, and participants show improvement in some measures of functioning and mood (Wimo et al., 1993, 1994).

There are several approaches to delivering services in adult day centers. There is no research evidence that any one model of service delivery is superior to another. For example, a social model has been developed by Little Havana Activities & Nutrition Centers of Dade County (Florida). The Little Havana Senior Center provides mental health, health, social, nutritional, transportation, and recreational services, emphasizing both remedial and preventive services.

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[7] Consultation-liaison models provide a bridge between psychiatry and the rest of medicine. In most models, a mental health specialist is called in as a consultant at the request of a primary care provider or works as a regular member of a team of health care providers.

The center focuses on the predominantly Cuban population of South Florida. Yet much more research is needed to demonstrate the relative effectiveness of different models of adult day services (Reifler et al., 1997).

Beyond adult day centers, other innovative models of community-based long-term care strive to incorporate mental health services. Few have been evaluated and none implemented on a wide scale. These models include the social/health maintenance organization (S/HMO) (Greenberg et al., 1988), On Lok Senior Services Program, and life care communities or continuing care retirement communities (Robinson, 1990b). These new features of the landscape of aging show promise, but there is insufficient evidence of cost-effectiveness and generalizability of these models, particularly the mental health component. Perhaps the lack of a research base and limited market account for the slow pace of their proliferation in the United States.

Nursing Homes

Most older adults live in the community and only a minority of them live in nursing homes; of the latter, about *two-thirds* have some kind of mental disorder (Burns, 1991). The majority have some type of dementia, while others have disabling depression or schizophrenia (Burns, 1991). Despite the high prevalence of people with mental disorders in nursing homes, these settings generally are ill equipped to meet their needs (Lombardo, 1994).

Deinstitutionalization of state mental hospitals beginning in the 1960s encouraged the expanded use of nursing homes for older adults with mental disorders. This trend was enhanced by Medicaid incentives to use nursing homes instead of mental hospitals. But the shift to nursing homes was not accompanied by alterations in care. In 1986, the Institute of Medicine issued a landmark report documenting inappropriate and inadequate care in nursing homes, including the excessive use of physical and chemical restraints (IOM, 1986). This subsequent visibility of problems prompted the passage in 1987 of the Nursing Home Reform Act (also known as the Omnibus Budget Reconciliation Act of 1987). This legislation restricted the inappropriate use of restraints and required preadmission screening for all persons suspected of having serious mental illness. The purpose of the screening was to exclude from nursing homes people with mental disorders who needed either more appropriate acute treatment in hospitals or long-term treatment in community-based settings. Preadmission screening also was designed to improve the quality of psychosocial assessments and care for nursing home residents with mental disorders. Nursing home placement is appropriate for patients with mental disorders if the disorders have produced such significant dysfunction that patients are unable to perform activities of daily living.

To meet the legislation's requirements, nursing homes must have the capacity to deliver mental health care. Such capacity depends on trained mental health professionals to deliver appropriate care and treatment. Unfortunately, prior to and even after passage of the Omnibus Budget Reconciliation Act of 1987, Medicaid policies discouraged nursing homes from providing specialized mental health services, and Medicaid reimbursements for nursing home patients have been too low to provide a strong incentive for participation by highly trained mental health providers (Taube et al., 1990). The emphasis on community-based care, combined with inadequate nursing home reimbursement policies, has limited the development of innovative mental health services in nursing homes. Major barriers persist in the delivery of appropriate care to mentally ill residents of nursing homes.

Services for Persons With Severe and Persistent Mental Disorders

Older adults with severe and persistent mental disorders (SPMD) are the most frequent users of long-term care either in community or institutional settings. SPMD in older adults includes lifelong and late-onset schizophrenia, delusional disorder, bipolar disorder, and recurrent major depression. It also includes Alzheimer's disease and other dementias (and related behavioral symptoms, including psychosis), severe treatment-refractory depression, or severe behavioral problems requiring intensive and prolonged psychiatric intervention. Although these groups of disorders have different courses of illness and outcomes, they have many overlapping clinical features, share the common need for mental health long-term care services, and are frequently treated together in long-term care settings (Burns, 1991; Gottesman et al., 1991; American Psychiatric Association, 1993). It is estimated that 0.8 percent of persons older than 55 years in the United States have SPMD (Kessler et al., 1996).

As a result of the dramatic downsizing and closure of state hospitals in past decades, 89 percent of institutionalized older persons with SPMD now live in nursing homes (Burns, 1991). However, institutions are expected to play a substantially smaller role than community-based settings in future systems of mental health long-term care (Bartels et al., in press). First, the majority of older adults with SPMD presently live in the community (Meeks & Murrell, 1997; Meeks et al., 1997) and prefer to remain there. Second, experience with the Preadmission Screening and Resident Review mandated by the Omnibus Budget Reconciliation Act of 1987 has been mixed. It may have slowed inappropriate admissions to nursing homes, restricted inappropriate use of restraints, and reduced overuse of psychotropic medications, but it did not otherwise improve the quality of mental health services (Lombardo, 1994). Furthermore, states' opposition to what they perceived to be Federal government interference in local health care policy and a general trend toward deregulation subsequently curtailed Federal nursing home reform. Finally, the growing costs of nursing home care are stimulating dramatic reforms in reimbursement and policy, including state mandates to limit Medicaid expenditures by decreasing nursing home beds and Federal reform by Medicare to implement prospective payment for nursing home services (Bartels & Levine, 1998). To accommodate the mounting number of individuals who have disorders requiring chronic care, future projections suggest the greatest growth in services will be in home and community-based settings (Institute for Health and Aging, 1996), increasingly financed through capitated and managed care arrangements.

Older adults with SPMD are high users of services (Cuffel et al., 1996; Semke & Jensen, 1997) and require mental health long-term care that is comprehensive, integrated, and multidisciplinary (Moak, 1996; Small et al., 1997; Bartels & Colenda, 1998). The mental health care needs of this population include specialized geropsychiatric services (Moak, 1996); integrated medical care (Moak & Fisher, 1991; Small et al., 1997); dementia care (Small et al., 1997; Bartels & Colenda, 1998); home and community-based long-term care; and residential and family support services, intensive case management, and psychosocial rehabilitation services (Aiken, 1990; Robinson, 1990a; Schaftt & Randolph, 1994; Lipsman, 1996). With adequate supports, older persons with SPMD can be maintained in the community, sometimes at lower cost, and with equal or improved quality of life in comparison with institutions (Bernstein & Hensley, 1988; Mosher-Ashley, 1989; Leff, 1993; Trieman et al., 1996).

However, current mental health policies have left many older persons with SPMD with decreased access to mental health care in both community and institutional settings (Knight et al., 1998). Community-based mental health services for older people are largely provided through the general medical sector, partly due to poor responsiveness to the needs of older people by community mental health organizations (Light et al., 1986). Yet reliance on the general medical sector also has not met their needs because of its focus on acute care (George, 1992). In addition, most home health agencies provide only limited short-term mental health care. The long-term care programs that exist primarily aid older adults with chronic physical disabilities or cognitive impairment but fail to address impairments in mood and behavior (Robinson, 1990a). An additional barrier is that the majority of community-residing older adults do not seek mental health services, except for medication (Meeks & Murrell, 1997), despite continued need (Meeks et al., 1997). Those without family support generally live in nursing homes, assisted living facilities, and board and care homes. These three are forms of residential care that offer some combination of housing, supportive services, and, in some cases, medical care. In short, more resources must be devoted to programs that integrate mental health rehabilitative services into long-term care in both community and institutional settings.

Financing Services for Older Adults

Financing policies furnish incentives that favor utilization of some services over others (e.g., nursing homes rather than state mental hospitals) or preclude the provision of needed services (e.g., mental health services in nursing homes). Details on financing and organizing mental health services, with a special focus on access, are presented in Chapter 6. Selected issues germane to older adults are addressed here.

Historically, Federal financing policy has imposed special limits on reimbursement for mental health services. Medicaid precluded payment for care in so-called "institutions for mental diseases," Medicaid's term for mental hospitals and the small percentage of nursing homes with specialized mental health services. This Medicaid policy provided a disincentive for the majority of nursing homes to specialize in delivering mental health services for fear of losing Medicaid payments (Taube et al., 1990). Under Medicare, the most salient limits were higher copayments for outpatient mental health services and a limited number of days for hospital care. Medicare's special limits on outpatient mental health services were changed over the past decade, resulting in significantly increased access to and utilization of such services (Goldman et al., 1985; Rosenbach & Ammering, 1997). The concern, however, is that the gains made as a result of policy changes easily could be eroded by the shift to managed care (Rosenbach & Ammering, 1997).

Increased Role of Managed Care

Projections are that 35 percent of all Medicare beneficiaries will be in managed care plans by the year 2007, amounting to approximately 15.3 million people (Komisar et al., 1997). Although the managed care industry has the potential to provide a range of integrated services for people with long-term care needs, managed care's awareness of and response to chronic care are rudimentary (Institute for Health and Aging, 1996). Despite the potential of systems of managed health care, such as HMOs, to provide comprehensive preventive, acute, and chronic care services, their current specialized geriatric programs and clinical case management for older persons tend to be inadequate or poorly implemented (Friedman & Kane, 1993; Pacala et al., 1995; Kane et al., 1997). In addition, older patients are likely to be poorly served in primary care settings (including primary care HMOs) because of minimal use of specialty providers and suboptimal pharmacological management (Bartels et al., 1997). Further, current systems lack the array of community support, residential, and rehabilitative services necessary to meet the needs of older persons with more severe mental disorders (Knight et al., 1995). These shortcomings are unlikely to be remedied until more research becomes available demonstrating cost-effective models for treating older people with mental illness.

Carved-In Mental Health Services for Older Adults

The types of mental health services available within managed care organizations vary greatly with respect to how services are provided. In some organizations, mental health care is directly integrated into the package of general health care services ("carved-in" mental health services), while it is provided in others through a contract with a separate specialty mental health organization that provides only these services and accepts the financial risk ("carved-out" mental health services).

Proponents of carved-in mental health services argue that this model better integrates physical and mental health care, decreases barriers to mental health care due to stigma, and is more likely to produce cost-offsets and overall savings in general health care expenditures. These features are particularly relevant to older persons, as they commonly have comorbid somatic disorders for which they take multiple medications that may affect mental disorders, often avoid specialty mental health settings, and incur significant health care expenses related to psychiatric symptoms (George, 1992; Paveza & Cohen, 1996; Moak, 1996; Riley et al., 1997). Unfortunately, mental health specialty services for older persons tend to be a low priority in managed health care organizations, by comparison with medical or surgical specialty services (Bartels et al., 1997). More importantly, carved-in mental health care may have superior potential for individuals with diagnoses such as minor depression and anxiety disorders but tends to shortchange older patients with SPMD who require intensive and long-term mental health care (Mechanic, 1998). The range of outreach, rehabilitative, residential, and intensive services needed for patients with SPMD is likely to exceed the capacity, expertise, and investment of most general health care providers.

Economic factors also may limit the usefulness of mental health carve-ins in serving the needs of older individuals with SPMD. First, evidence from private sector health plans suggests that without mandated parity, insurers offer inferior coverage of mental health care (Frank et al., 1997b, 1997c). Furthermore, if providers or payers compete for enrollees, there is strong incentive to avoid enrollees expected to have higher costs from mental health problems (e.g., older persons with SPMD). To avoid such discrimination, equal coverage of mental health care would have to be mandated through legislation on mental health parity or through specialized contract requirements with managed care organizations.

Carved-Out Mental Health Services for Older Adults

Proponents of mental health service carve-outs for older persons argue that separate systems of financing and services are likely to be superior for individuals needing specialty mental health services, especially those with SPMD. In particular, advocates suggest that carved-out mental health organizations have superior technical knowledge, specialized skills, a broader array of services, greater numbers and varieties of mental health providers with experience treating severe mental disorders, and a willingness and commitment to service high-risk populations (Riley et al., 1997). From an economic perspective, since competition is largely over the carve-out contract with the payer (generally a public organization or an employer), there is less incentive to compete on risk selection, and risk adjustment becomes unnecessary. In addition, mental health carve-out organizations may be better equipped to provide rehabilitative and community support mental health services necessary to care for older persons with SPMD. Finally, growth of innovative outpatient alternatives could be stimulated by reinvestment of savings by the payer from any decrease in inpatient service use.

Unfortunately, research is lacking on outcomes and costs for older persons with SPMD in mental health carve-outs. A carve-out arrangement could lead to adverse clinical outcomes in older patients due to fragmentation of medical and mental health care services in a population with high risk of complications of comorbidity and polypharmacy. Also, from a financial perspective, the combination of physical and mental comorbidities seen in older adults, especially those with SPMD, may reduce the economic advantages of carved-out services (Bazemore, 1996; Felker et al., 1996; Tsuang & Woolson, 1997). If the provider cannot appropriately manage services and costs associated with the combination of somatic and mental health disorders, anticipated savings may not materialize. Furthermore, fragmentation of reimbursement streams would likely complicate the assessment of cost-effectiveness or cost-offsets. For example, apparent savings of mental health carve-outs under Medicare actually may be due to shifting costs when an individual is also covered under Medicaid. In this situation, Medicaid may cover prescription drugs, long-term care, and other services that are not paid for by Medicare. In order to offer true efficiencies, Medicare mental health carve-outs need to find a way to bridge the fragmentation of financing care for older persons.

Outcomes Under Managed Care

There do not appear to be any studies of mental health outcomes for older adults under managed care. In general, the available research on mental health outcomes for other adults consistently finds that managed care is successful at reducing mental health care costs (Busch, 1997; Sturm, 1997), yet clinical outcomes (especially for the most severely and chronically ill) are mixed and difficult to interpret due to differences in plans and populations served. Several studies suggest that outcomes under managed care for younger adults are as favorable as, or better than, those under fee-for-service (Lurie et al., 1992; Cole et al., 1994). In contrast, others report that the greater use of nonspecialty services for mental health care under managed care is associated with less cost-effective care (Sturm & Wells, 1995), and that older and poor chronically ill patients may have worse health outcomes or outcomes that vary substantially by site and patient characteristics (Ware et al., 1996). A recent review of health outcomes for both older and younger adults in the managed care literature (Miller & Luft, 1997) concluded that there were no consistent patterns that suggested worse outcomes. However, negative outcomes were more common in patients with chronic conditions, those with diseases requiring more intensive services, low-income enrollees in worse health, impaired or frail elderly, or home health patients with chronic conditions and diseases. These risk factors apply to older adults with SPMD, suggesting that this group is at high risk for poor outcomes under managed care programs that lack specialized long-term mental health and support services. To definitively address the question of mental health outcomes for older persons under managed care, appropriate outcome measures for older adults with mental illness will need to be developed and implemented in the evolving health care delivery systems (Bartels et al., in press).

Other Services and Supports

Older adults and their families depend on a multiplicity of supports that extend beyond the health and mental health care systems. Patients and caregivers need access to education, support networks, support and self-help groups, respite care, and human services, among other supports (Scott-Lennox & George, 1996). These services assume heightened importance for older people who are living alone, who are uncomfortable with formal mental health services, or who are inadequately treated in primary care. Services and supports appear to be instrumental not only for the patient but also for the family caregiver, as this section explains, but research on their efficacy is sparse. The strongest evidence surrounds the efficacy of services for family caregivers. Support for family caregivers is crucial for their own health and mental health, as well as for controlling the high costs of institutionalization of the family member in their care. The longer the patient remains home, the lower the total cost of institutional care for those who eventually need it.

Support and Self-Help Groups

Support groups, which are an adjunct to formal treatment, are designed to provide mutual support, information, and a broader social network. They can be professionally led by counselors or psychologists, but when they are run by consumers[x] or family members, they are known as self-help groups. The distinction is somewhat clouded by the fact that mental health professionals and community organizations often aid self-help groups with logistical support, start-up assistance, consultation, referrals, and education (Waters, 1995). For example, self-help support groups sponsored by the Alzheimer's Association use professionals to provide consultation to groups orchestrated by lay leaders.

Support groups for people with mental disorders and their families have been found helpful for adults (see Chapter 4). Participation in support groups, including self-help groups, reduces feelings of isolation, increases knowledge, and promotes coping efforts. What little research has been conducted on older people is generally positive but has been limited mostly to caregivers (see later section) and widows (see below), rather than to older people with mental disorders.

Despite the scant body of research, there is reason to believe that support and self-help group participation is as beneficial, if not more beneficial, for older people with mental disorders. Older people tend to live alone and to be more socially isolated than are other people. They also are less comfortable with formal mental health services. Therefore, social networks established through support and self-help groups are thought to be especially vital in preventing isolation and promoting health. Support programs also can help reduce the stigma associated with mental illness, to foster early detection of illnesses, and to improve compliance with formal interventions.

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[x] Consumers are people engaged in and served by mental health services.

Earlier sections of this chapter documented the untoward consequences of prolonged bereavement: severe emotional distress, adjustment disorders, depression, and suicide. Outcomes have been studied for two programs of self-help for bereavement. One program, They Help Each Other Spiritually (THEOS), had robust effects on those who were more active in the program. Those widows and widowers displayed the improvements on health measures such as depression, anxiety, somatic symptoms, and self-esteem (Lieberman & Videka-Sherman, 1986). The other program, Widow to Widow: A Mutual Health Program for the Widowed, was developed by Silverman (1988). The evaluation in a controlled study found program participants experienced fewer depressive symptoms and recovered their activities and developed new relationships more quickly (Vachon, 1979; Vachon et al., 1980, 1982).

Education and Health Promotion

There is a need for improved consumer-oriented public information to educate older persons about health promotion and the nature of mental health problems in aging. Understanding that mental health problems are not inevitable and immutable concomitants of the aging process, but problems that can be diagnosed, treated, and prevented, empowers older persons to seek treatment and contributes to more rapid diagnosis and better treatment outcomes.

With respect to health promotion, older persons also need information about strategies that they can follow to maintain their mental health. Avoiding disease and disability, sustaining high cognitive and physical function, and engaging with life appear to be important ways to promote mental and physical health (Rowe & Kahn, 1997). The two are interdependent.

Established programs for health promotion in older people include wellness programs, life review, retirement, and bereavement groups (see review by Waters, 1995). Although controlled evaluations of these programs are infrequent, bereavement and life review appear to be the best studied. Bereavement groups produce beneficial results, as noted above, and life review has been found to produce positive outcomes in terms of stronger life satisfaction, psychological well-being, self-esteem, and less depression (Haight et al., 1998). Life review also was investigated through individualized home visits to homebound older people in the community who were not depressed but suffered chronic health conditions. Life review for these older people was found to improve life satisfaction and psychological well-being (Haight et al., 1998).

Another approach to promoting mental health is to develop a "social portfolio," a program of sound activities and interpersonal relationships that usher individuals into old age (Cohen, 1995b). While people in the modern work force are advised to plan for future economic security—to strive for a balanced financial portfolio—too little attention is paid to developing a balanced social portfolio to help to plan for the future. Ideally, such a program will balance *individual* with *group* activities and *high mobility/energy* activities requiring significant physical exertion with *low mobility/energy* ones. The social portfolio is a mental health promotion strategy for helping people develop new strengths and satisfactions.

Families and Caregivers

Among the many myths about aging is that American families do not care for their older members. Such myths are based on isolated anecdotes as opposed to aggregate data. Approximately 13 million caregivers, most of whom are women, provide unpaid care to older relatives (Biegel et al., 1991). Families are committed to their older members and provide a spectrum of assistance, from hands-on to monetary help (Bengston et al., 1985; Sussman, 1985; Gatz et al., 1990; Cohen, 1995a). Problems occur with older individuals who have no children or spouse, thereby reducing the opportunity to receive family aid. Problems also occur with the "old-old," those over 85 whose children are themselves old and, therefore, unable to provide the same intensity of hands-on help that younger adult children can provide. These special circumstances highlight the need for careful attention to planning for mental health service delivery to older individuals with less access to family or informal support systems.

Conversely, a large and growing number of older family members care for chronically mentally ill and mentally retarded younger adults (Bengston et al., 1985; Gatz et al., 1990; Eggebeen & Wilhelm, 1995). Too little is known about ways to help the afflicted younger individuals and their caregiving parents. Families are eager to help themselves, and society needs to find ways to better enable them to do so.

There is a great need to better educate families about what they can do to help promote mental health and to prevent and treat mental health problems in their older family members. Families fall prey to negative stereotypes that little can be done for late-life mental health problems. They need to know that mental health problems in later life, like physical health problems, can be treated. They need to understand how to better recognize symptoms or signals of impending mental health problems among older adults so that they can help their loved ones receive early interventions. They need to know what services are available, where they can be found, and how to help their older relatives access such help when necessary.

The plight of family caregivers is pivotal. As noted earlier, the burden of caring for an older family member places caregivers at risk for mental and physical disorders. Virtually all studies find elevated levels of depressive symptomatology among caregivers, and those using diagnostic interviews report high rates of clinical depression and anxiety (Schultz et al., 1995). Ensuring their mental and physical health is not only vital for their well-being but also is vital for the older people in their care. Support groups and services aimed at caregivers can improve their health and quality of life, can improve management of patients in their care, and can delay their institutionalization.

Communities and Social Services

Family support is often supplemented by enduring long-term relationships between older people and their neighbors and community, including religious, civic, and public organizations (Scott-Lennox & George, 1996). Linkages to these organizations instill a sense of belonging and companionship. Such linkages also provide a safety net, enabling some older people to live independently in spite of functional decline.

While the vast majority of frail and homebound older people receive quality care at home, abuse does occur. Estimates vary, but most studies find rates of abuse by caregivers (either family or nonfamily members) to range up to 5 percent (Coyne et al., 1993; Scott-Lennox & George, 1996). Abuse is generally defined in terms of being either physical, psychological, legal, or financial. The abuse is most likely to occur when the patient has dementia or late-life depression, conditions that impart relatively high psychological and physical burdens on caregivers (Coyne et al., 1993). A recent report by the Institute of Medicine describes the range of interventions for protection against abuse of older people, including caregiver participation in support groups and training programs for behavioral management (especially for Alzheimer's disease) and social services programs (e.g., adult protective services, casework, advocacy services, and out-of-home placements). While there are very few controlled evaluations of these services (IOM, 1998), communities need to ensure that there are programs in place to prevent abuse of older people. Programs can incorporate any of a number of effective psychosocial and support interventions for patients with Alzheimer's disease and their caregivers—interventions that were presented earlier in this section and the section on Alzheimer's disease.

Communities need to ensure the availability of adult day care and other forms of respite services to aid caregivers striving to care for family members at home. They also can provide assistance to self-help and other support programs for patients and caregivers. In the process of facilitating or providing services, communities need to consider the diversity of their older residents—racial and ethnic diversity, socioeconomic diversity, diversity in settings where they live, and diversity in levels of general functioning. Such diversity demands comprehensive program planning, information and referral services (including directories of what is available in the community), strong outreach initiatives, and concerted ways to promote accessibility. Moreover, each component of the community-based delivery system targeting older adults should incorporate a clear focus on mental health. Too often, attention to mental health services for older people and their caregivers is negligible or absent, despite the fact, as noted earlier, that mental health problems and caregiver distress are among the leading reasons for institutionalization (Lombardo, 1994). Important life tasks remain for individuals as they age. Older individuals continue to learn and contribute to society, in spite of physiologic changes due to aging and increasing health problems.

Conclusions

1. Important life tasks remain for individuals as they age. Older individuals continue to learn and contribute to the society, in spite of physiologic changes due to aging and increasing health problems.
2. Continued intellectual, social, and physical activity throughout the life cycle are important for the maintenance of mental health in late life.
3. Stressful life events, such as declining health and/or the loss of mates, family members, or friends often increase with age. However, persistent bereavement or serious depression is not "normal" and should be treated.
4. Normal aging is not characterized by mental or cognitive disorders. Mental or substance use disorders that present alone or co-occur should be recognized and treated as illnesses.
5. Disability due to mental illness in individuals over 65 years old will become a major public health problem in the near future because of demographic changes. In particular, dementia, depression, and schizophrenia, among other conditions, will all present special problems in this age group:
    a. Dementia produces significant dependency and is a leading contributor to the need for costly long-term care in the last years of life;
    b. Depression contributes to the high rates of suicide among males in this population; and
    c. Schizophrenia continues to be disabling in spite of recovery of function by some individuals in mid to late life.
6. There are effective interventions for most mental disorders experienced by older persons (for example, depression and anxiety), and many mental health problems, such as bereavement.
7. Older individuals can benefit from the advances in psychotherapy, medication, and other treatment interventions for mental disorders enjoyed by younger adults, when these interventions are modified for age and health status.
8. Treating older adults with mental disorders accrues other benefits to overall health by improving the interest and ability of individuals to care for themselves and follow their primary care provider's directions and advice, particularly about taking medications.
9. Primary care practitioners are a critical link in identifying and addressing mental disorders in older adults. Opportunities are missed to improve mental health and general medical outcomes when mental illness is underrecognized and undertreated in primary care settings.
10. Barriers to access exist in the organization and financing of services for aging citizens. There are specific problems with Medicare, Medicaid, nursing homes, and managed care.

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CHAPTER 6

ORGANIZING AND FINANCING MENTAL HEALTH SERVICES

This chapter examines what recent research has revealed about the organization and financing of mental health services as well as the cost and quality of those services. The discussion places emphasis on the tremendous growth of managed care and the attempts to gain parity in insurance. Understanding these issues can inform the decisions made by people with mental health problems and disorders, as well as their family members and advocates, and health care administrators and policymakers. Earlier chapters reviewed data on the occurrence of mental disorders in the population at large and described the treatment system. In each stage of the life cycle, issues related to mental health services have been discussed, including, for example, the breadth of mental health and human services involved in caring for children with mental health problems and disorders; deinstitutionalization and its role in shaping contemporary mental health services for children and adults; the problems associated with discontinuity of care in a fragmented service system; and the importance of primary care medical providers in meeting the mental health needs of older persons. Special mental health services concerns such as homelessness, criminalization of persons with mental illness, and disparities in access to and utilization of mental health services due to racial, cultural, and ethnic identities as well as other demographic characteristics have been discussed throughout the report.

There are four main sections in this chapter. The first section provides an overview of the current system of mental health services. It describes where people get care and how they use services. The next section presents information on the costs of care and trends in spending. The third section discusses the dynamics of insurance financing and managed care. It also addresses both positive and adverse effects of managed care on access and quality and describes efforts to guard against untoward consequences of aggressive cost-containment policies. The final section documents some of the inequities between general medical and mental health care and describes efforts to correct them through legislation, regulation, and financing changes.

Overview of the Current Service System

The Structure of the U.S. Mental Health Service System

A broad array of services and treatments exists to help people with mental illnesses—as well as those at particular risk of developing them—to suffer less emotional pain and disability and live healthier, longer, and more productive lives. Mental disorders and mental health problems are treated by a variety of caregivers who work in diverse, relatively independent, and loosely coordinated facilities and services—both public and private—that researchers refer to, collectively, as the *de facto mental health service system* (Regier et al., 1978; Regier et al., 1993).

About 15 percent of all adults and 21 percent of U.S. children and adolescents use services in the de facto system each year. The system is usually described as having four major components or sectors:

- The *specialty mental health* sector consists of mental health professionals such as psychiatrists, psychologists, psychiatric nurses, and psychiatric social workers who are trained specifically to treat people with mental disorders. The great bulk of specialty treatment is now provided in outpatient settings such as private office-based practices or in private or public clinics. Most acute hospital care is now provided in special psychiatric units of general hospitals or beds scattered throughout general hospitals. Private psychiatric hospitals and residential treatment centers for children and adolescents provide additional intensive care in the private sector. Public sector facilities include state/county mental hospitals and multiservice mental health facilities, which often coordinate a wide range of outpatient, intensive case management, partial hospitalization, and inpatient services. Altogether, slightly less than 6 percent of the adult population and about 8 percent of children and adolescents (ages 9 to 17) use specialty mental health services in a year.

- The *general medical/primary care* sector consists of health care professionals such as general internists, pediatricians, and nurse practitioners in office-based practice, clinics, acute medical/surgical hospitals, and nursing homes. More than 6 percent of the adult U.S. population use the general medical sector for mental health care, with an average of about 4 visits per year—far lower than the average of 14 visits per year found in the specialty mental health sector.[1] The general medical sector has long been identified as the initial point of contact for many adults with mental disorders; for some, these providers may be their only source of mental health services. However, only about 3 percent of children and adolescents contact general medical physicians for mental health services; the human services sector (see below) plays a much larger role in their care.
- The *human services* sector consists of social services, school-based counseling services, residential rehabilitation services, vocational rehabilitation, criminal justice/prison-based services, and religious professional counselors. In the early 1980s, about 3 percent of U.S. adults used mental health services from this sector. But by the early 1990s, the National Comorbidity Survey (NCS) revealed that 5 percent of adults used such services. For children, school mental health services are a major source of care (used by 16 percent), as are services in the child welfare and juvenile justice systems, which serve about 3 percent.
- The *voluntary support network* sector, which consists of self-help groups, such as 12-step programs and peer counselors, is a rapidly growing component of the mental and addictive disorder treatment system. The Epidemiologic Catchment Area (ECA) study demonstrated that about 1 percent of the adult population used self-help groups in the early 1980s; the NCS showed a rise to about 3 percent in the early 1990s.

Table 6-1 summarizes the percentage of U.S. adults who use different sectors of the de facto mental health treatment system. (There is overlap across these sectors because some people use services in multiple sectors.) Table 6-2 summarizes the percentage of U.S. children and adolescents using various sectors of this system.

Table 6-1. Proportion of adult population using mental/addictive disorder services in one year

Total Health Sector	11%*
Specialty Mental Health	6%
General Medical	6%
Human Services Professionals	5%
Voluntary Support Network	3%
Any of Above Services	15%

*Subtotals do not add to total due to overlap.

Source: Regier et al., 1993; Kessler et al., 1996

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[1] The National Comorbidity Survey, using a single interview requiring a 12-month recall period, determined that 4 percent of adults sought mental or addictive treatment services from primary care physicians. With a more intensive examination of primary health care use involving three interviews about service use during a 1-year period in the Epidemiologic Catchment Area study, more than 6 percent of adults indicated that they specifically spoke with their general medical physicians about their "emotions, nerves, drugs or alcohol."

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Table 6-2. **Proportion of child/adolescent populations (ages 9–17) using mental/addictive disorder services in one year**

Total Health Sector	9%*
Specialty Mental Health	8%
General Medical	3%
Human Services Professionals	17%*
School Services	16%
Other Human Services	3%
Any of Above Services	21%

*Subtotals do not add to total due to overlap.
Source: Shaffer et al., 1996

The Public and Private Sectors

The de facto mental health service system is divided into public and private sectors. The term "public sector" refers both to services directly operated by government agencies (e.g., state and county mental hospitals) and to services financed with government resources (e.g., Medicaid, a Federal-state program for financing health care services for people who are poor and disabled, and Medicare, a Federal health insurance program primarily for older Americans and people who retire early due to disability). Publicly financed services may be provided by private organizations. The term "private sector" refers both to services directly operated by private agencies and to services financed with private resources (e.g., employer-provided insurance). Funding for the de facto mental health service system is discussed later in the report.

State and local government has been the major payer for public mental health services historically and remains so today. Since the mid-1960s, however, the role of the Federal government has increased. In addition to Medicare and Medicaid, the Federal government funds special programs for adults with serious mental illness and children with serious emotional disability. Although small in relation to state and local funding, these Federal programs provide additional resources. They include the Community Mental Health Block Grant, Community Support programs, the PATH program for people with mental illness who are homeless, the Knowledge Development and Application Program, and the Comprehensive Community Mental Health Services for Children and Their Families Program.

The fact that 16 percent of the U.S. adult population—largely the working poor—have no health insurance at all is the focus of considerable policy activity. Many others are inadequately insured. Initiatives designed to increase enrollment for selected populations include the newly created Child Health Insurance Program, which provides block grants to states for coverage of children not eligible for Medicaid.

These federally funded public sector programs buttress the traditional responsibility of state and local mental health systems and serve as the mental health service "safety net" and "catastrophic insurer" for those citizens with the most severe problems and the fewest resources in the United States. The public sector serves particularly those individuals with no health insurance, those who have insurance but no mental health coverage, and those who exhaust limited mental health benefits in their health insurance.

Each sector of the de facto mental health service system has different patterns and types of care and different patterns of funding. Within the specialty mental health sector, state- and county-funded mental health services have long served as a safety net for people unable to obtain or retain access to privately funded mental health services. The general medical sector receives a relatively greater proportion of Federal Medicaid funds, while the voluntary support network sector, staffed principally by people with mental illness and their families, is largely funded by private donations of time and money to emotionally supportive and educational groups. The relative quality of care in these various sectors is a matter of intense interest and discussion, although there is little definitive research to date.

Effective functioning of the mental health service system requires connections and coordination among many sectors (public–private, specialty–general health, health–social welfare, housing, criminal justice, and education). Without coordination, it can readily become organizationally fragmented, creating barriers to access. Adding to the system's complexity is its dependence on many streams of funding, with their sometimes competing incentives. For example, if as part of a Medicaid program reform, financial incentives lead to a reduction in admissions to psychiatric inpatient units in general hospitals and patients are sent to state mental hospitals instead, this cost containment policy conceivably could conflict with a policy directive to reduce the census of state mental hospitals.

The public and private parts of the de facto mental health system treat distinct populations with some overlap. As shown in Table 6-1, 11 percent of the U.S. population use specialty or general medical mental health services each year. Nearly 10 percent of the population—almost all users—received some care in private facilities, while 2 percent of the population received care in public facilities. About 1 percent of the population used inpatient care; of these, one-third received care in the public sector, suggesting that those requiring more intensive services rely more heavily on the public safety net (Regier et al., 1993; Kessler et al., 1994). Nonetheless, many people with severe and persistent illness now receive at least some of their care in the private sector. This makes it important to ensure that the private sector can meet the full treatment needs of this population.

Patterns of Use

Adults

Americans use the mental health service system in complex ways, or patterns. A total of about 15 percent of the U.S. adult population use mental health services in any given year. These data come from two epidemiologic surveys: the Epidemiologic Catchment Area (ECA) study of the early 1980s and the National Comorbidity Survey (NCS) of the early 1990s. Those surveys defined mental illness according to the prevailing editions of the *Diagnostic and Statistical Manual of Mental Disorders* (i.e., DSM-III and DSM-IIIR) and defined mental health services in accordance with the "de facto" system described above. Figure 6-1 presents a hierarchy of sectors in the treatment system (i.e., specialty mental health, general medical, and other human services).[2] About 6 percent of the adult population use specialty mental health care; 5 percent of the population receive their mental health services from general medical and/or human services providers, and 3 to 4 percent of the population receive their mental health services from other human service professionals or self-help groups. (The overlap across these latter two sectors accounts for these figures totaling more than 15 percent) (Figure 6-1).

Also, slightly more than *half* of the 15 percent of the population that use mental health services have a specific mental or addictive disorder (8 percent), while the remaining portion has a mental health problem or a disorder not included in the ECA or NCS (7 percent). The surveys estimate that during a 1-year period, about one in five American adults—or 44 million people—have diagnosable mental disorders, according to reliable, established criteria. To be more specific, 19 percent of the adult U.S. population have a mental disorder alone (in 1 year); 3 percent have both mental and addictive disorders; and 6 percent have addictive disorders alone. Consequently, about 28 percent of the population have either a mental *or* addictive disorder (Regier et al., 1993; Kessler et al., 1994).

Given that 28 percent of the population have a diagnosable mental or substance abuse disorder and only 8 percent of adults both have a diagnosable disorder and use mental health services, one can conclude that less than one-third of adults with a diagnosable mental disorder receives treatment in one year. In short, a substantial *majority* of those with specific mental disorders do not receive treatment. Figure 6-1 depicts the 28 percent of the U.S. adult population who meet full criteria for a mental or addictive disorder, and illustrates that 8 percent receive mental health services while 20 percent do *not* receive such services in a given year.

Among the service users with specific disorders, between 30 and 40 percent perceived some need for care. However, most of those with disorders who did not seek care believed their problems would go away by themselves or that they could handle them on their own (Kessler et al., 1997). In a recent 1998 Robert Wood Johnson national household telephone survey, 11 percent of the population perceived a need for mental or addictive services, with about 25 percent of these reporting difficulties in obtaining needed care (Sturm & Sherbourne, 1999). Worry about costs was listed as the highest reason for not receiving care, with 83 percent of the uninsured and 55 percent of the privately insured listing this reason. The inability to obtain an appointment soon enough because of an insufficient supply of services was listed by 59 percent of those with Medicaid but by far fewer of those with private insurance.

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[2] For those who use more than one sector of the service system, preferential assignment is to the most specialized level of mental health treatment in the system.

Children and Adolescents

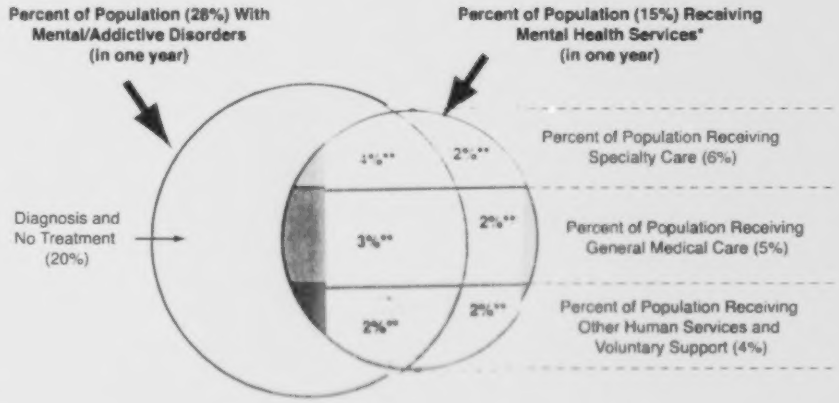
Comparable data on service use by children and adolescents with diagnoses of mental disorder and at least minimal impairment only recently have been obtained from a National Institute of Mental Health (NIMH) multisite survey of children and adolescents ages 9 to 17 years (Shaffer et al., 1996). Results from this survey are summarized in Table 6-2 and in Figure 6-2.

Although 9 percent of the entire child/adolescent sample received some mental health services in the health sector (that is, the general medical sector and specialty mental health sector), the largest provider of mental health services to this population was the school system. As shown in Figure 6-2, nearly 11 percent of the child/adolescent sample received their mental health services exclusively from the schools or the human services sector (with no services from the health sector); another 5 percent (not shown in Figure 6-2) received school services in addition to health sector services. Many children served by schools do not have diagnosable mental health conditions covered in available surveys—some may have other diagnoses such as adjustment reactions or acute stress reactions. In addition, 1 percent of children and adolescents received their mental health services from human service professionals, such as those in child welfare and juvenile justice. The latter is a setting under increasing scrutiny as the result of pending Federal legislation. At present, child data are unavailable that would exactly match the adult data on service use (analyzed by diagnostic severity and by public versus private sectors).

Almost 21 percent of children and adolescents (ages 9 to 17) had some evidence of distress or impairment associated with a specific diagnosis and also had at least a minimal level of impairment on a global assessment measure. Almost half of this group (almost 10 percent of the child/adolescent population) had some treatment in one or more sectors of the de facto mental health service system, and the remainder (more than 11 percent of the population) received no treatment in any sector of the health care system. This translates to a majority with mental disorders not receiving any care. Of the 21 percent of the young population receiving any mental health services, slightly less than half (about 10 percent) met full criteria for a mental disorder diagnosis; the remainder (more than 11 percent of the population) received diagnostic or treatment services for mental health problems, conditions that do not fully meet diagnostic criteria (Shaffer et al., 1996).

In summary, the mental health treatment system is a dynamic array of services accessed by patients with different levels of disorder and severity, as well as different social and medical service needs and levels and types of insurance financing. Disparities in access due to sociocultural factors have been described in earlier sections of this report. In a system in which substantial numbers of those with even the most severe mental illness do not receive any mental health care in a year, the match between service use and service need is clearly far from perfect. Neither the number nor the proportion of people with mental health problems who need or want treatment is yet established, and many factors influence perceived need for treatment, including severity of symptoms and functional disability as well as cultural factors. But obviously not everyone with a diagnosable mental disorder perceives a need for treatment, and not all who desire treatment have a currently diagnosable disorder. Providing access

Figure 6-1. Annual prevalence of mental/addictive disorders and services for adults

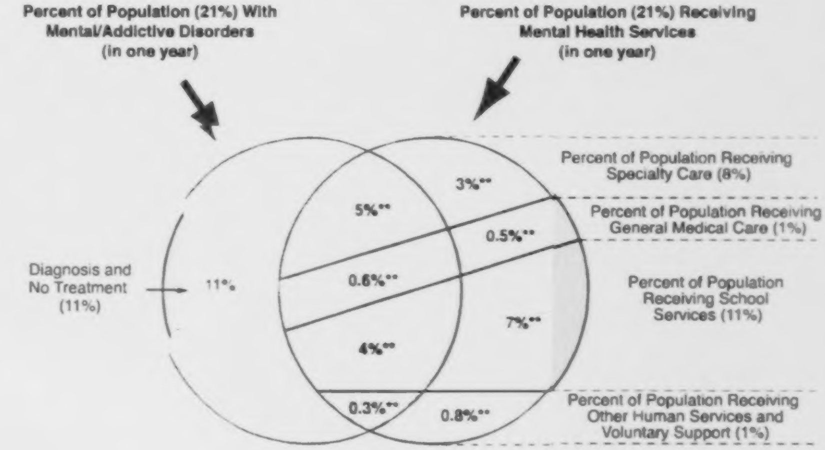


* Due to rounding, it appears that 9 percent of the population has a diagnosis and receives treatment. The actual figure is closer to 8 percent, as stated in the text. It also appears that 6 percent of the population receives services but has no diagnosis, due to rounding. The actual total is 7 percent, as stated in the text.

** For those who use more than one sector of the service system, preferential assignment is to the most specialized level of mental health treatment in the system.

Sources: Regier et al., 1993; Kessler et al., 1996

Figure 6-2. Annual prevalence of mental/addictive disorders and services for children



** For those who use more than one sector of the service system, preferential assignment is to the most specialized level of mental health treatment in the system.

Source: Shaffer et al., 1996

to appropriate mental health services is a fundamental concern for mental health policymakers in both the public and private arenas.

The Costs of Mental Illness

As many of the preceding chapters have indicated, mental disorders impose an enormous emotional and financial burden on ill individuals and their families. They are also costly for our Nation in reduced or lost productivity (indirect costs) and in medical resources used for care, treatment, and rehabilitation (direct costs).

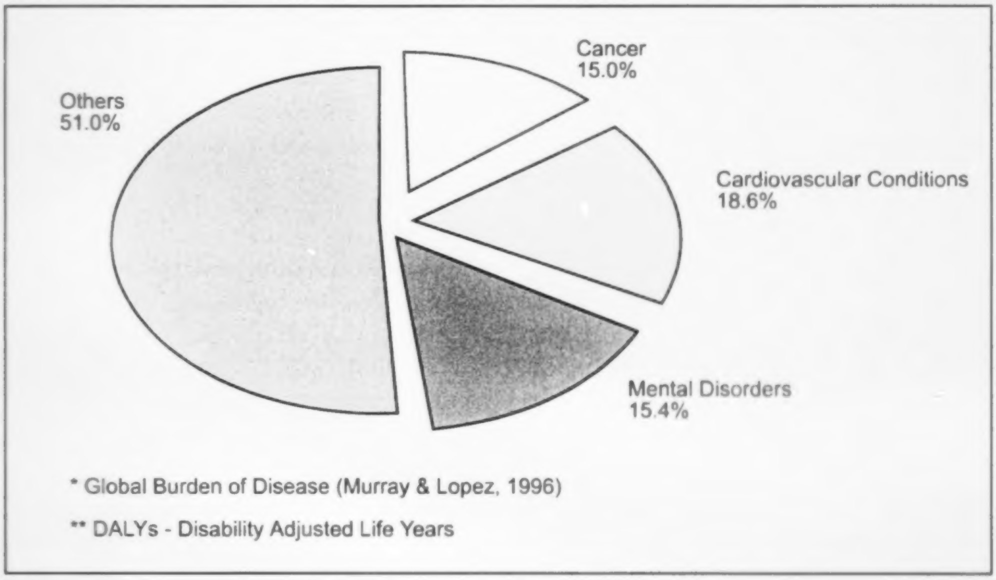
Indirect Costs

The *indirect costs* of all mental illness imposed a nearly $79 billion loss on the U.S. economy in 1990 (the most recent year for which estimates are available) (Rice & Miller, 1996). Most of that amount ($63 billion) reflects morbidity costs—the loss of productivity in usual activities because of illness. But indirect costs also include almost $12 billion in mortality costs (lost productivity due to premature death), and almost $4 billion in productivity losses for incarcerated individuals and for the time of individuals providing family care. For schizophrenia alone, the total indirect cost was almost $15 billion in 1990. These indirect cost estimates are conservative because they do not capture some measure of the pain, suffering, disruption, and reduced productivity that are not reflected in earnings.

The fact that morbidity costs comprise about 80 percent of the indirect costs of all mental illness indicates an important characteristic of mental disorders: Mortality is relatively low, onset is often at a younger age, and most of the indirect costs are derived from lost or reduced productivity at the workplace, school, and home (Rupp et al., 1998).

The Global Burden of Disease, a recent publication of the World Bank and the World Health Organization, reported on a study of the indirect costs of mental disorders associated with years lived with a disability, with and without years of life lost due to premature death. Disability Adjusted Life Years (DALYs) are now being used as a common metric for describing the burden of disability and premature death resulting from the full range of mental and physical disorders throughout the world (Figure 6-3). A striking finding from the study has been that mental disorders account for more than 15 percent of the burden of disease in

Figure 6-3. Global burden of disease*—DALYs worldwide—1990**



* Global Burden of Disease (Murray & Lopez, 1996)

** DALYs - Disability Adjusted Life Years established market economies; unipolar major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder are identified as among the top 10 leading causes of disability worldwide (Murray & Lopez, 1996).

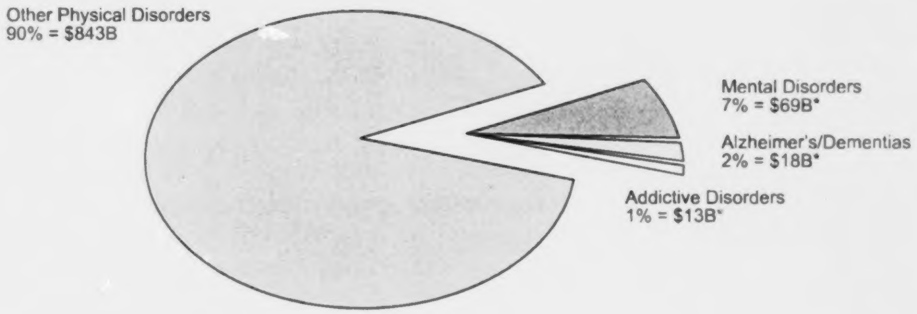
Direct Costs

Mental health expenditures for treatment and rehabilitation are an important part of overall health care spending but differ in important ways from other types of health care spending. Many mental health services are provided by separate specialty providers—such as psychiatrists, psychologists, social workers, and nurses in office practice—or by facilities such as hospitals, multiservice mental health organizations, or residential treatment centers for children. Insurance coverage of mental health services is typically less generous than that for general health, and government plays a larger role in financing mental health services compared to overall health care.

In 1996, the United States spent more than $99 billion for the direct treatment of mental disorders, as well as substance abuse, and Alzheimer's disease and other dementias (Figure 6-4).

More than two-thirds of this amount ($69 billion or more than 7 percent of total health spending) was for mental health services. Spending for direct treatment of substance abuse was almost $13 billion (more than 1 percent of total health spending), and that for Alzheimer's disease and other dementias was almost $18 billion (almost 2 percent of total health spending) (Figure 6-4).[3]

Figure 6-4. 1996 National health accounts, $943 billion total—$99 billion* mental, addictive, and dementia disorders



* Figures add to more than $99 billion due to rounding.

Source: Mark et al., 1998, and additional analyses performed by Mark et al. for this report.

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[3] Figure 6-4 comes from the spending estimates project conducted by the Center for Mental Health Services and the Center for Substance Abuse Treatment, Substance Abuse and Mental Health Services Administration. It is limited to spending for formal treatment of disorders and excludes spending for most services not ordinarily classified as health care. Some of these data come directly from the most recent report published by this project (Mark et al., 1998), while others are based on unpublished data. Further, minor modifications in estimation methodology have been made since the Mark et al. (1998) report to meet the special requirements of the Surgeon General's report. The estimates presented here differ from those published previously by Rice and her colleagues (Rice et al., 1990) in several important respects. First, they are limited to a definition of mental illness that more closely reflects what most payers regard as mental disorders. Diagnostic codes such as mental retardation and non-mental health comorbid conditions, which were included in the Rice study, have not been used. Second, they are based on data sources that were not available at the time of the Rice study. Finally, they result from a different approach to estimation, which emphasizes linkage to the National Health Accounts published by the Health Care Financing Administration.

Although Alzheimer's disease and other dementias are not discussed further in this chapter, the reader should note that the definition of serious mental illness promulgated by the Center for Mental Health Services includes these disorders. Further, care of these patients is a major role of the public mental health system.

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Despite the historical precedent for linking all these disorder groups together for diagnostic and cost accounting purposes, they are handled differently by payers and providers. A majority of private health insurance plans have a benefit that combines coverage of mental illness and substance abuse. However, most of the treatment services for mental illness and for substance abuse are separate (and use different types of providers), as are virtually all of the public funds for these services. This separation causes problems for treating the substantial proportion of individuals with comorbid mental illness and substance abuse disorders, who benefit from treating both disorders together (Drake et al., 1998).

Alzheimer's disease and other dementias historically have been considered as both mental and somatic disorders. However, recent efforts to destigmatize dementias and improve care have removed some insurance coverage limitations. Once mostly the province of the public sector, Alzheimer's disease now enjoys more comprehensive coverage, and care is better integrated into the private health care system. Inequities in coverage are diminishing (U.S. Department of Health and Human Services Task Force on Alzheimer's Disease, 1984; Goldman et al., 1985).

As indicated, coverage differs for treatment of substance abuse and Alzheimer's disease. With respect to financing policy, both conditions are outside the scope of this report (although some services aspects of Alzheimer's disease are discussed in Chapter 5); thus, they will not be included in the spending estimates that follow.

Mental Health Spending

Of the $69 billion spent in 1996 for diagnosis and treatment of mental illness (see Figure 6-5), more than 70 percent was for the services of specialty providers, with most of the remainder for general medical services providers.[4] The distribution for all types of providers is shown in the figure.

Spending by the Public and Private Sectors

Funding for the mental health service system comes from both public and private sources [Table 6-3 and Figure 6-6 (percent distribution) and Table 6-4 (dollar distribution and per capita mental health costs)]. In 1996, approximately 53 percent ($37 billion) of the funding for mental health treatment came from public payers. Of the 47 percent ($32 billion) of expenditures from private sources, more than half ($18 billion) were from private insurance. Most of the remainder was out-of-pocket payments. These out-of-pocket payments include copayments from individuals with private insurance, copayments and prescription costs not covered by Medicare or Medigap (i.e., supplementary) insurance, and payment for direct treatment from the uninsured or insured who choose not to use their insurance coverage for mental health care.

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[4] In estimating mental health expenditures, spending can be categorized by provider type, which includes both general medical service providers and specialty mental health providers. Since spending for mental health services in the human services sector is not covered by health insurance or included in the national health accounts, neither total costs nor total spending estimates for mental health services are covered under these direct cost figures. Indirect costs generally include estimates of lost productivity as well as disability insurance and the costs of treating those with mental illness in the criminal justice system. Hence, it is not possible to provide completely parallel analyses of the prevalence of mental disorders in the population, the prevalence of treatment in different service sectors, and expenditures in the treatment system. However, the estimate given here is the best approximation of that intent.

For purpose of these analyses, general medical service providers include community hospitals, nursing homes, non-psychiatrist physicians, and home health agencies. An intermediate funding category is that of prescription medications, which are prescribed in both general medical and specialty mental health settings. Other than prescription medications, 18 percent of total mental health funds are allocated in this analysis to the general medical sector, which provides some mental health services to slightly more than half of all persons (about 6 percent of the population) using any services in the health system during 1 year.

Specialty providers include psychiatric hospitals, psychiatrists, office-practice psychologists and counselors (including social workers and psychiatric nurses), residential treatment centers for children, and multiservice mental health organizations. These mental health specialists provided some mental health services to nearly 6 percent of the population—also about half of all people requesting such services from health and mental health services in the health system.

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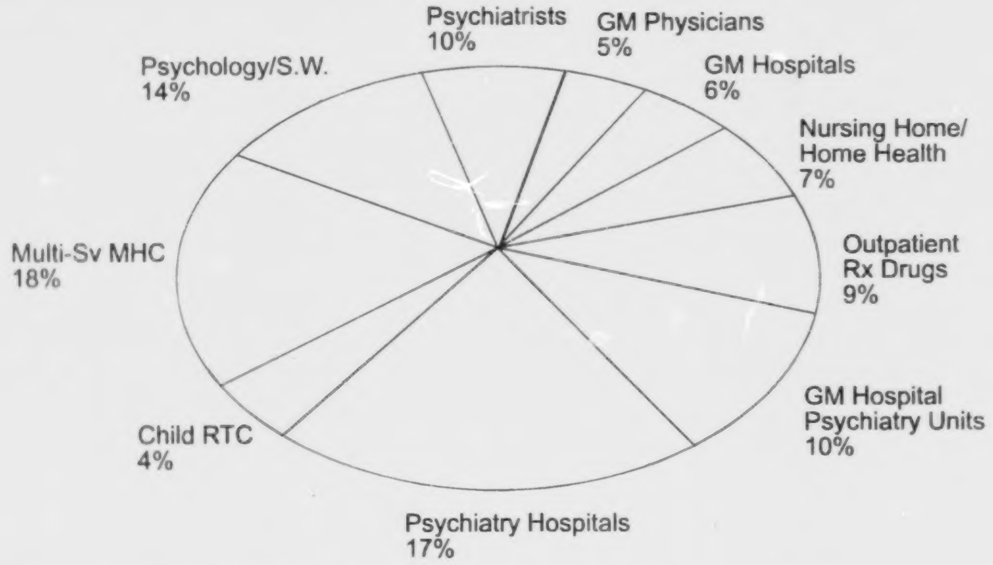
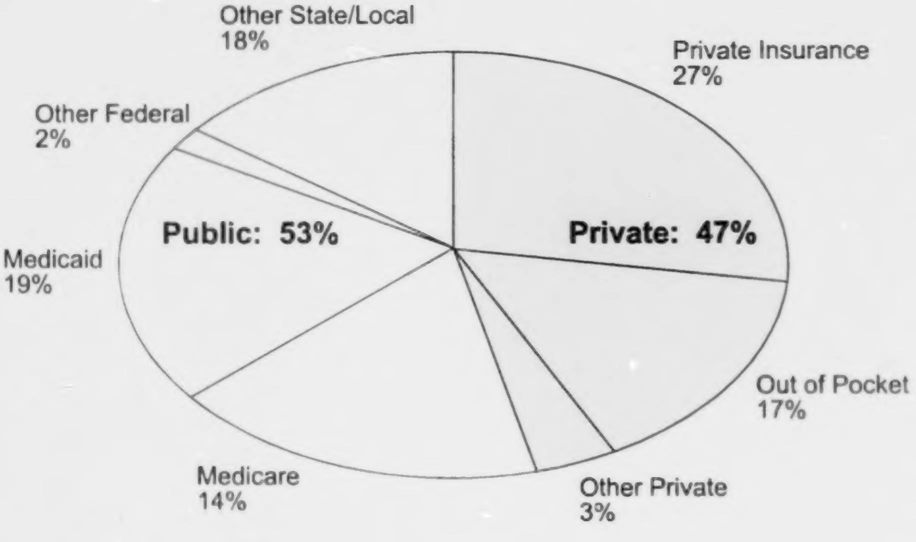
Figure 6-5. 1996 National health accounts, $69 billion total mental health expenditures by provider type



Source: Mark et al., 1998 (Revised)

Figure 6-6. Mental health expenditures by payer—1996 (total = $69 billion)



Source: Mark et al., 1998 (Revised)

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Table 6-3. Distribution of 1996 U.S. population and mental disorder direct costs by insurance status

Insurance Status	Population	Direct Costs
Private	63%*	47%
Public	***	53%
Medicare	13%**	14%
Medicaid	12%**	19%
Uninsured	***	—
State/Local	16%	18%
Other Federal	***	2%
Total	100%	100%

* About 70 percent of the population has some private insurance—reflecting the fact that 7 percent of the population has both Medicare and Medigap or other dual private insurance coverage. Although 61 percent of the population has employment-based private insurance, this percentage also includes some military insurance coverage.

** Since 2 percent of the population has both Medicare and Medicaid insurance coverage, adding this duplicated count to each insurance category results in the first column adding to a duplicated total of 104 percent.

*** Although some state/local/and other Federal government support goes to those who are underinsured in the private and public insured groups, these funds are primarily allocated to the uninsured population.

Source: Mark et al., 1998 (Revised)

Table 6-4. Population, spending, and per capita mental health costs by insurance status (1996)

Insurance Status	Number (millions)	Spending ($ billions)	Per Capita ($ per year)
Private	167.5	32.3	193
Insurance Payment		18.4	
Out-of-Pocket Payment		11.7	
Other Private		2.2	
Medicare	30.6	9.8	320
Medicaid	27.0	13.0	481
Other and Uninsured	41.7	13.9	333
SPMI*	5.1	12.4	2,431
Other	36.6	1.5	41
Total	266.8	69.0	259

* Severe and persistent mental illness

Source: Mark et al., 1998, and calculations by D. Regier, personal communication, 1999

Trends in Spending

Between 1986 and 1996, mental health expenditures grew at an average annual growth rate of more than 7 percent (Table 6-5). Because of changes in population, reimbursement policies, and legislative and regulatory requirements during this decade, the share of mental health funding from public sources grew from 49 percent to 53 percent. Overall, the rate of growth in the public sector was slightly more than 8 percent per year (Medicare and Medicaid, both about 9 percent; state/local government, nearly 8 percent).

In the private sector, out-of-pocket costs increased only 3 percent, which, together with the private insurance increases of almost 9 percent, resulted in a net private cost increase of little more than 6 percent—significantly lower than the increase found in the public sector.

Table 6-5. Mental health expenditures in relation to national health expenditures, by source of payer, annual growth rate (1986–1996)

	Average Annual Growth Rate (1986–1996)	
	Mental Health Care	All Health Care
Private		
Out-of-Pocket Payment	3%	5%
Private Insurance	9%	9%
Other Private	7%	7%
Total Private	6%	7%
Public		
Medicare	9%	10%
Medicaid	9%	13%
Other Federal Government	4%	6%
State/Local Government	8%	10%
Total Public	8%	10%
Total Expenditures	7%	8%

Source: Mark et al., 1998 (Revised)

Among the fastest-rising expenses for mental health services were outpatient prescription drugs, which account for about 9 percent of total mental health direct costs (Figure 6-5). Although these medications are prescribed in both specialty and general medical sectors, they are increasingly being covered under general medical rather than mental health private insurance benefits.

The higher than average growth rate (almost 10 percent) of spending for prescription drugs reflects, in part, the increasing availability and application of medications of demonstrable efficacy in treating mental disorders. Estimates from the National Ambulatory Medical Care Survey show that the number of visits during which such medication was prescribed increased from almost 33 million in 1985 to almost 46 million in 1994. Only one-third of psychotropic medications are now prescribed by psychiatrists, with two-thirds prescribed by primary care physicians and other medical specialists (Pincus et al., 1998). Although Medicaid covers 21 percent of drug costs (and state/local/other Federal government covers 4 percent), Medicare does not cover prescription drugs. Although many older adults have supplemental insurance that does cover prescription drugs, the failure to cover any prescription drugs under Medicare is a barrier to effective treatment among the elderly who cannot afford supplemental insurance.

Mental Health Compared With Total Health

Mental health spending figures acquire more meaning when they are compared with those for all health care. Annually, the Health Care Financing Administration produces estimates of this spending. These estimates include nearly all of the expenditures presented for mental health services. However, some specialty providers who work in social service industries are excluded from the national health care spending estimates. Accordingly, mental health estimates require adjustment to allow direct comparison with these national figures, reducing the total from $69 billion cited earlier to $66 billion (Table 6-6).

Table 6-6. Mental health expenditures in relation to national health expenditures, by source of payer, 1996

	Expenditures in Billions (1996)		
	Mental Health Care	All Health Care	Percentage
Private			
Client Out-of-Pocket	$11	$171	6%
Private Insurance	$17	$292	6%
Other Private	$2	$32	5%
Total Private	$30	$495	6%
Public			
Medicare	$10	$198	5%
Medicaid	$13	$140	9%
Other Federal Government	$1	$41	3%
State/Local Government	$12	$69	18%
Total Public	$36	$447	8%
Total Expenditures	$66	$943	7%

Source: Mark et al., 1998 (Revised)

Estimated total health care expenditures were $943 billion in 1996. Of this amount, 7 percent was for mental health services. Table 6-6 describes expenditures on mental health services as a percentage of national health spending by source of payment. The significance of mental health spending for various payers varies from a low of only 3 percent of "other" Federal government spending to a high of 18 percent of health care expenditures by state and local governments.

Between 1986 and 1996, spending for mental health treatment grew more slowly than health care spending in general, increasing by more than 7 percent annually, compared with health care's overall rate of more than 8 percent (see Table 6-5). This difference may stem from the greater reliance of mental health services on managed care cost-containment methods during this period. Increased efficiency could account for a slower rate of growth in mental health care expenditures. Slowing of the growth rate in the public sector may also be due to other Federal and state government policies, such as limitations in states' ability to use certain Medicaid funds to support state mental hospitals and states' greater emphasis on community-based outpatient care as opposed to inpatient care. Finally, it may also reflect the greater contribution of institutional care, particularly in nursing homes, to total health care figures. Changes in these components affect overall growth rates more in general health care than in mental health care.

For most provider categories, the rise in mental health spending was not much different than spending growth rates for personal health care, with the exception of home health (higher) and nursing home (lower) expenditures. For various types of payers, spending growth in mental health care has been about the same or less than that in general health care. Mental health spending in Medicare, Medicaid, and other Federal programs has grown more slowly than overall program spending. For private sources, the growth rate of mental health out-of-pocket expenditures has been below that of total out-of-pocket spending (see Table 6-5).

During the past two decades there have been important shifts in what parties have final responsibility for paying for mental health care. The role of direct state funding of mental health care has been reduced, whereas Medicaid funding of mental health care has grown in relative importance. This is in part due to substantial funding offered to the states by the Federal government. One consequence of this shift is that Medicaid program design has become very influential in shaping the delivery of mental health care. State mental health authorities, however, continue to be an important force in making public mental health services policy, working together with state Medicaid programs. Considerable administrative responsibility for mental health services has devolved to local mental health authorities in recent years (Shore & Cohen, 1994).

Private insurance coverage has played a somewhat more limited role in mental health financing in the past decade. Various cost containment efforts have been pursued aggressively in the private sector through the introduction of managed care. There is also some emerging evidence on the imposition of new benefit limits on coverage for mental health services (HayGroup, 1998). At the same time private insurance coverage for prescription drugs has expanded dramatically over the past 15 years. In this area, insurance coverage for mental health treatments is on par with coverage for other illnesses. Accompanying this pattern of private insurance coverage are the availability of innovative new prescription drugs aimed at treating major mental illnesses and a shift in mental health spending in private insurance toward pharmaceutical agents.

In summary, spending for mental health care has declined as a percentage of overall health spending over the past decade. Further, public payers have increased their share of total mental health spending. Some of the decline in resources for mental health relative to total health care may be due to reductions in inappropriate and wasteful hospitalizations and other improvements in efficiency. However, it also may reflect increasing reliance on other (non-mental health) public human services and increased barriers to service access.

Financing and Managing Mental Health Care

History of Financing and the Roots of Inequality

Private health insurance is generally more restrictive in coverage of mental illness than in coverage for somatic illness. This was motivated by several concerns. Insurers feared that coverage of mental health services would result in high costs associated with long-term and intensive psychotherapy and extended hospital stays. They also were reluctant to pay for long-term, often custodial, hospital stays that were guaranteed by the public mental health system, the provider of "catastrophic care." These factors encouraged private insurers to limit coverage for mental health services (Frank et al., 1996).

Some private insurers refused to cover mental illness treatment; others simply limited payment to acute care services. Those who did offer coverage chose to impose various financial restrictions, such as separate and lower annual and lifetime limits on care (per person and per episode of care), as well as separate (and higher) deductibles and copayments. As a result, individuals paid out-of-pocket for a higher proportion of mental health services than general health services and faced catastrophic financial losses (and/or transfer to the public sector) when the costs of their care exceeded the limits.

Federal public financing mechanisms, such as Medicare and Medicaid, also imposed limitations on coverage, particularly for long-term care, of "nervous and mental disease" to avoid a complete shift in financial responsibility from state and local governments to the Federal government. Existence of the public sector as a guarantor of "catastrophic care" for the uninsured and underinsured allowed the private sector to avoid financial risk and focus on acute care of less impaired individuals, most of whom received health insurance benefits through their employer (Goldman et al., 1994).

Goals for Mental Health Insurance Coverage

The purpose of health insurance is to protect individuals from catastrophic financial loss. While the majority of individuals who use mental health services incur comparatively small expenses, some who have severe illness face financial ruin without the protection afforded by insurance. For people with health insurance, the range of covered benefits and the limits imposed on them ultimately determine where they will get service, which, in turn, affects their ability to access necessary and effective treatment services. Adequate mental health treatment resources for large population groups require a wide range of services in a variety of settings, with sufficient flexibility to permit movement to the appropriate level of care. A 1996 review of the evidence for the efficacy of well-documented treatments (Frank et al., 1996) suggested that covered services should include the following:

- Hospital and other 24-hour services (e.g., crisis residential services);
- Intensive community services (e.g., partial hospitalization);
- Ambulatory or outpatient services (e.g., focused forms of psychotherapy);
- Medical management (e.g., monitoring psychotropic medications);
- Case management;
- Intensive psychosocial rehabilitation services; and
- Other intensive outreach approaches to the care of individuals with severe disorders.

Since resources to provide such services are finite, insurance plans are responsible for allocating resources to support treatment. Each type of insurance plan has a different model for matching treatment need with insurance support for receiving services.

Patterns of Insurance Coverage for Mental Health Care

Health insurance, whether funded through private or public sources, is one of the most important factors influencing access to health and mental health services. In 1996, approximately 63 percent of the U.S. population had private insurance, 13 percent had Medicare as a primary insurer (with about 7 percent also having supplemental private insurance), 12 percent had Medicaid (2 percent had dual Medicaid/Medicare), and 16 percent were uninsured (Bureau of the Census, 1996) (Table 6-3.)

Most Americans (84 percent) have some sort of insurance coverage—primarily private insurance obtained through the workplace. However, its adequacy for mental health care is extremely variable across types of plans and sponsors. Of the more than $32 billion spent for mental health services for people with private insurance, more than $18 billion came from that insurance, almost $12 billion came from client out-of-pocket payments, and more than $2 billion came from other private sources. For these more than 167 million people, the per capita expenditure was $193 per person per year (Table 6-4).

Slightly more than 13 percent of the U.S. population are entitled to Medicare, which includes mental health coverage. The nearly $10 billion spent for mental health coverage under Medicare for nearly 31 million people reflects an average per capita expenditure of $320 per year.

Nearly 12 percent of U.S. adults (27 million low-income individuals on public support) receive Medicaid coverage (with more than 2 percent having dual Medicare/Medicaid coverage). With per capita expenditures of $481 a year for mental health services, the average cost of this coverage is 2.5 times higher than that in the private sector. An explanation for this higher average cost is the severity of illness of this population and greater intensity of services needed to meet their needs.

Finally, more than $12 billion (other than Medicaid funds) from state/local government and more than $1 billion from other Federal government block grant and Veterans Affairs funds contribute a total of almost $14 billion to cover mental health services for the uninsured. Most (75 percent) of the uninsured are members of employed families who cannot afford to purchase insurance coverage. Individuals with severe and persistent mental illness who are uninsured have the highest annual costs, leaving few resources for treatment for those with less severe disorders (see Table 6-4). By applying the technique of Frank and colleagues (1994) to 1996 funding patterns, it is estimated that public sector costs for seriously mentally ill patients receiving care in the public sector (about 5.1 million people or 1.9 percent of the population) are about $2,430 per year. As a result, although it is only a rough estimate, only about $40 per year per capita is available for those uninsured with less severe mental illness.

State mental health policymakers have begun to blend funding streams from Medicaid and the state public mental health expenditures under Medicaid "waivers," which offer the potential of purchasing private insurance for certain public beneficiaries who have not been eligible for Medicaid. This new option has recently been raised as a means of concentrating public mental health services on forensic and other long-term intensive care programs not covered by private insurance (Hogan, 1998). Given the extremely low level of funding for the uninsured with less severe mental illness, the recently implemented Federal legislation to fund a State Child Health Insurance Program (CHIP) could result in considerably increased coverage for previously uninsured children. It is noteworthy that CHIP benefits vary from state-to-state particularly for mental health coverage.

Traditional Insurance and the Dynamics of Cost Containment

From the time they were introduced in 1929 until the 1990s, fee-for-service (indemnity) plans, such as Blue Cross/Blue Shield, were the most common form of health insurance. Insurance plans would identify the range of services they considered effective for the treatment of all health conditions and then reimburse physicians, hospitals, and other health care providers for the usual and customary fees charged by independent practitioners. To prevent the overuse of services, insurance companies would often require patients to pay for some portion of the costs out-of-pocket (i.e., co-insurance) and would use annual deductibles, much as auto insurance companies do, to minimize the administrative costs of processing small claims.

For most health insurance plans covering somatic illness, to protect the *insured*, costs above a certain "catastrophic limit" would be borne entirely by the insurance company. To protect the *insurer* against potentially unlimited claims, however, "annual" or "lifetime limits"—often as high as $1 million—would be imposed for most medical or surgical conditions. It was expected that any expenses beyond that limit would become the responsibility of the patient's family.

In contrast, in the case of coverage for mental health services, insurance companies often set lower annual or lifetime limits, for reasons discussed in the following paragraphs, to protect themselves against costly claims, leaving patients and their families exposed to much greater personal financial risks. The legacy of the public mental health system safety net as the provider of catastrophic coverage encouraged such practices. Further, when federal financing mechanisms such as Medicare and Medicaid were introduced, they also limited coverage of long-term care of "nervous and mental disease" to avoid shifting financial responsibility from state and local government to the Federal government.

Economists have observed that for potential insurers of mental health care or general health care, two financial concerns are key: *moral hazard* and *adverse selection*. The terms are technical, but the concepts are basic. Moral hazard reflects a concern that if people with insurance no longer have to pay the full costs of their own care, they will use more services—services that they do not value at their full cost. To control moral hazard, insurers incorporate cost-sharing and care management into their policies. Adverse selection reflects a concern that, in a market with voluntary insurance or multiple insurers, plans that provide the most generous coverage will attract individuals with the greatest need for care, leading to elevated service use and costs for those insurers independent of their efficiency in services provision. To control adverse selection, insurers try to restrict mental health coverage to avoid enrolling people with higher mental health service needs.

Both forces are at work in the insurance market, and they tend to be stronger for coverage of some mental health services than for some general health services. There is evidence of moral hazard, for example, from the RAND Health Insurance Experiment, which showed that increased use of insured services in response to decreased out-of-pocket costs for consumers (known as "demand response") is twice as great for outpatient mental health services (mostly psychotherapy) as for all ambulatory health services taken together (Manning et al., 1989). The RAND study did not include a sufficient number of individuals who used inpatient care or who were severely disabled to make a determination of the effect of changes in price on hospital care or on outpatient use by individuals with severe mental disorders.

While these economic forces are important, insurer responses to them may have been exaggerated. In the fee-for-service insurance system, for example, some insurers have addressed their concerns about moral hazard by assigning higher cost-sharing to mental health services. Coverage limitations, imposed to control costs, have been applied unevenly, however, and without full consideration of their consequences. In particular, higher cost-sharing, such as placing a 50 percent copayment on outpatient psychotherapy, may reduce moral hazard and inappropriate use, but it may also reduce appropriate use. Limits on coverage may reduce adverse selection but leave people to bear catastrophic costs themselves.

In addition, such measures do not address the issue of fairness in coverage policy. In particular, although similar levels of price response and presumed moral hazard occur in other areas of health care, mental health coverage is singled out for special cost-sharing arrangements. There may be a rationale for some level of differential cost-sharing, but such policies are fair only if the benefit design policies are applied to all services in which demand is highly responsive to price.

Managed Care

Managed care represents a confluence of several forces shaping the organization and financing of health care. These include the drive to deliver more highly individualized, cost-effective care; a more health-promoting and preventive orientation (often found in health maintenance organizations, or HMOs); and a concern with cost containment to address the problem of moral hazard. Managed care implies a range of financing and payment strategies that depart in important ways from traditional fee-for-service indemnity insurance. Managed care strategies have resulted in dramatic savings in a wide range of settings over the past decade (Bloom et al., 1998; Callahan et al., 1995; Christianson et al., 1995; Coulam & Smith, 1990; Goldman et al., 1998; Ma & McGuire, 1998).

Major Types of Managed Care Plans

Health maintenance organizations were the first form of managed care. Originally developed by the Kaiser Foundation to provide health services to company employees, these large group practices initiated contracts to provide all medical services on a prepaid, per capita basis. Medical staff members were originally salaried and not paid on a fee-for-service basis, as is the case in most other financing arrangements. However, in recent years, some HMOs have developed networks of physicians—so-called Independent Practice Associations, or IPAs—who are paid on a fee-for-service basis and function under common management guidelines.

Health maintenance organizations initially treated only those mental disorders that were responsive to short-term treatment, but they reduced copayments and deductibles for any brief therapy. There was an implicit reliance on the public mental health system for treatment of any chronic or severe mental disorder—especially those for whom catastrophic coverage was needed.

Preferred Provider Organizations (PPOs) are managed care plans that contract with networks of providers to supply services. Providers are typically paid on a discounted fee-for-service basis. Enrollees are offered lower cost-sharing to use providers on the "preferred" list but can use non-network providers at a higher out-of-pocket cost.

Point-of-Service (POS) plans are managed care plans that combine features of prepaid (or capitated) and fee-for-service insurance. Enrollees can choose to use a network provider at the time of service. A significant copayment typically accompanies use of non-network providers. Although few plans are purely of one type, an important difference between a PPO and a POS is that in a PPO plan, the patient may select any type of covered care from any in-network provider, while in a POS, use of in-network services must be approved by a primary care physician.

In *Carve-out Managed Behavioral Health Care*, segments of insurance risk—defined by service or disease—are isolated from overall insurance risk and covered in a separate contract between the payer (insurer or employer) and the carve-out vendor. Even with highly restrictive admission criteria, many HMOs have recently found it cost effective to carve out mental health care for administration by a managed behavioral health company, rather than relying on in-house staff. This arrangement permits a larger range of services than can be provided by existing staff without increasing salaried staff and management overhead costs. Carve-outs generally have separate budgets, provider networks, and financial incentive arrangements. Covered services, utilization management techniques, financial risk, and other features vary depending on the particular carve-out contract. The employee as a plan member may be unaware of any such arrangement. These separate contracts delegate management of mental health care to specialized vendors known as *managed behavioral health care organizations (MBHOs)*.

There are two general forms of carve-outs: *payer carve-outs* and *health plan subcontracts*. In payer carve-outs, an enrollee chooses a health plan for coverage of health care with the exception of mental health and must enroll with a separate carve-out vendor for mental health care. Examples of payer carve-outs include the state employee health plans of Ohio and Massachusetts. In health plan subcontracts, administrators of the general medical plan arrange to have mental health care managed by a carve-out vendor or MBHO; the plan member does not have to take steps to select mental health coverage. Examples of payer carve-outs include health plans associated with Prudential and Humana.

The Ascent of Managed Care

Over the past decade, the pace of change in U.S. health insurance has been striking. In 1988, insurance based on fee-for-service was the predominant method of financing health care. But in the ensuing decade, various management techniques were added such that insurance that used "unmanaged fee-for-service" as its payment mechanism plummeted from 71 percent to 15 percent (HayGroup, 1998). Managed care arrangements (HMO, PPO, or POS plans), which fundamentally alter the way in which health care resources are allocated, now cover the majority (56 percent) of Americans (Levit & Lundy, 1998). During the 1988–1998 decade, PPO plans rose from being 13 percent to 34 percent of primary medical plans, with a similar rapid rise in HMO plans from 9 percent to 24 percent. Point-of-service (POS) plans rose more slowly as the principal medical plan, from 12 percent in 1990 to 20 percent in 1998 (HayGroup, 1998).

Managed care has also made significant inroads into publicly funded health care. Between 1988 and 1997, Medicaid enrollees in managed care rose from 9 percent to 48 percent, while Medicare enrollees in managed care increased from 5 percent to 14 percent. Most Medicaid and Medicare managed care growth has occurred since 1994. In Medicaid, growth is primarily focused on the population receiving Temporary Aid to Needy Families support (as opposed to the population with severe and chronic mental illness, eligible for Medicaid because of Supplemental Security Income-eligible disability) (HayGroup, 1998).

In 1999, almost 177 million Americans with health insurance (72 percent) were enrolled in managed behavioral health organizations. This represents a 9 percent increase over enrollment in 1998 (OPEN MINDS, 1999). This administrative mechanism has changed the incentive structure for mental health professionals, with "supply-side" controls (e.g., provider incentives) replacing "demand-side" controls (e.g., benefit limits) on service use and cost. In addition, the privatization of service delivery is increasing in the public sector. As a result of these changes, access to specific types of mental health services is increasingly under the purview of managed behavioral care companies and employers.

It is difficult to know precisely how many people are enrolled in various forms of carve-out plans. Recent reports estimate that 35 percent of employers with more than 5,000 employees have created payer carve-outs, while only 5 percent of firms with fewer than 500 employees have adopted them (Mercer/Foster-Higgins, 1997). A survey of 50 large HMOs revealed that roughly half of HMO enrollees were enrolled in carve-out plans (OPEN MINDS, 1999). The carve-out concept has also been adopted by a number of state Medicaid programs. At most recent count, 15 states are using payer carve-out arrangements to manage mental health care (Substance Abuse and Mental Health Services Administration [SAMHSA], 1998). More than 20 states use carve-out arrangements to manage non-Medicaid public sector services.

As the states have adopted Medicaid managed care for mental health, at least two distinct models have emerged. States that entered managed care early have tended to issue contracts to private sector organizations to perform both administrative (payments, network development) and management (utilization review) functions. States that entered managed care more recently have tended to contract administrative functions with Administrative Services Organizations (ASOs), while retaining control of management functions. Under any of these arrangements, financial risk for the provision of care to a particular population can be distributed in a variety of ways (Essock & Goldman, 1995).

As the foregoing discussion indicates, mental health services associated with private insurance, public insurance, and public direct-service programs often have managed mental health care arrangements that are organized differently than are overall health services. These arrangements have emerged mostly within the past decade. The next section describes how the ascent of managed care has shifted patterns of resource allocation toward financial incentives aimed at providers, organizational structure, and administrative mechanisms and away from the use of benefit design (e.g., using copayments and annual deductibles) meant to encourage consumer cost-sharing. As a result, cost control and care management are accomplished through a more complicated set of policies than at any time in the recent past, and benefit design is no longer the only factor in determining service allocation or predicting costs to a health insurer.

Dynamics of Cost Controls in Managed Care

In a managed care system, the moral hazard of unnecessary utilization need not be addressed through benefit design. Utilization typically is controlled at the level of the provider of care, through a series of financial incentives and through direct management of the care. For example, managed care reduces cost in part by shifting treatment from inpatient to outpatient settings, negotiating discounted hospital and professional fees, and using utilization management techniques to limit unnecessary services. In this fashion, at least theoretically, unnecessary utilization, the moral hazard, is eliminated at the source, on a case-by-case basis.

Adverse selection may be addressed through regulations, such as mandates in coverage that require all insurers in a market to offer the same level of services. In this way, no one insurer runs the risk that offering superior coverage will necessarily attract people who are higher utilizers of care. Efforts to regulate adverse selection may not produce the intended effect, however, when insurers who offer the same services use management techniques to control costs by restricting care to those who use services most intensely—effectively denying care to those who most need it. In such instances, patients with the greatest needs might become concentrated in plans with the most generous management of care. This may lead to financial losses for such plans or encourage them to cut back on services for those who need care most or to divert resources from other beneficiaries.

As managed care grows, the structure of the industry changes, with companies merging and disappearing. Managed behavioral health care organizations now cover approximately 177 million Americans, with only three companies controlling 57 percent of all insured persons (or 91 million covered lives) (OPEN MINDS, 1999). However, the range of management controls currently applied to enrollees in covered plans extends from simple utilization review of hospitalizations on an administrative services only (ASO) contract to prepaid, at-risk contracts with extensive employee assistance plan (EAP) screening and networks of eligible mental health specialists and hospitals providing services for discounted fees. If and when mental health service benefits expand, it is possible for managed behavioral health plans to tighten the level of supply-side controls to maintain costs at a desired level.

Some consumers and consumer advocates have expressed concern that the management measures used to cut the costs of health care may also lower its quality and/or accessibility. Although this issue was addressed by the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry and by current Patient Bill of Rights legislation, more research is needed to understand the effects of industry competition on costs, access, and quality. (See Appendix 6-A for Patient Bill of Rights.)

Managed Care Effects on Mental Health Services Access and Quality

Managed care demonstrably reduces the cost of mental health services (Ma & McGuire, 1998; Goldman et al., 1998; Callahan et al., 1995; Bloom et al., 1998; Christianson et al., 1995; Coulam & Smith, 1990). That was one of its goals—to remove the excesses of overutilization, such as unnecessary hospitalization, and to increase the number of individuals treated by using more cost-effective care. This was to be accomplished through case-by-case "management" of care. The risk of cost-containment, however, is that it can lead to undertreatment. Research is just beginning on how managed care cost-reduction techniques affect access and quality. Excessively restrictive cost-containment strategies and financial incentives to providers and facilities to reduce specialty referrals, hospital admissions, or length or amount of treatment may ultimately contribute to lowered access and quality of care. These restrictions pose particular risk to people on either end of the severity spectrum: individuals with mental health problems may be denied services entirely, while the most severely and persistently ill patients may be undertreated. These risks must be seen, however, in the context of similar problems inherent in fee-for-service practice. Access and quality problems and the failure to treat those most in need predate managed care.

Impact on Access to Services

Despite considerable concern that managed care cost reductions may inappropriately restrict access to mental health services, the actual impact of these reductions has received relatively little systematic study. In addition, there are currently no benchmark standards for access to specialty mental health services.[5] A system to measure access and track it over time is clearly needed. Establishing targets for treated prevalence[6] is also problematic because the appropriate level and type of service utilization for specific population groups is only beginning to be documented (McFarland et al., 1998).

The term "access to mental health services" refers generally to the ability to obtain treatment with appropriate professionals for mental disorders.[7] Having health insurance—and the nature of its coverage and administration—are critical determinants of such access. But so are factors such as the person's clinical status and personal and sociocultural factors affecting desire for care; knowledge about mental health services and the effectiveness of current treatments; the level of insurance copayments, deductibles, and limits; ability to obtain adequate time off from work and other responsibilities to obtain treatment; and the availability of providers in close proximity, as well as the availability of transportation and child care. In addition, because the stigma associated with mental disorders is still a barrier to seeking care, the availability of services organized in ways that reduce stigma—such as employee assistance programs—can provide important gateways to further treatment when necessary.

A small number of studies provide a limited picture of access to managed behavioral health care. It has been found that the proportion of individuals receiving mental health treatment varies considerably across managed behavioral health plans (National Advisory Mental Health Council, 1998). Some long-term case studies of managed care's impact on access find that the probability of using mental health care—especially outpatient care—increases after managed behavioral health care is implemented in private insurance plans (Goldman et al., 1998).

Impact on Quality of Care

The quality of care within health systems has been assessed traditionally on three dimensions: (1) the *structure* of the health care organization or system; (2) the *process* of the delivery of health services; and (3) the *outcomes* of service for consumers (Donabedian, 1966). Many of these dimensions are being tapped in current efforts to assess—and, it is hoped, ultimately improve—the overall quality of mental health care in the United States. These include the use of accreditation practices, clinical- and systems-level practice guidelines, outcome measures and "report cards," and systems-level performance indicators. For example, to maximize the potential mental health benefit of patients' contact with the primary health care sector, which 70 to 80 percent of all Americans visit at least once a year, guidelines and treatment algorithms have been developed. The Agency for Health Care Policy and Research has developed comprehensive guidelines for the treatment of depression in primary care settings (1993) as well as recommendations for the treatment of schizophrenia (Patient Outcome Research Team, Lehman & Steinwachs, 1998). Also funded by the Agency is the Depression PORT that will soon release findings on the quality and cost of the treatment of depression in managed, primary care practice (Wells et al., in press). In addition, multiple studies are now under way to develop better coordination between primary care physicians and mental health specialists for management of both chronic and acute mental disorders (Katon et al., 1997; Wells, 1999). These studies are described in more detail in Chapters 4 and 5.

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[5] Between the early 1980s and 1990s—prior to the dominance of managed care—about 5.8 percent of U.S. adults used some type of specialty mental health outpatient services in any year. This rate now can be used as one reference point for assessing subsequent changes in access to mental health services, although there is no evidence on the appropriateness of this care.

[6] Researchers and administrators often report access in terms of *treated prevalence* or *penetration rates*. These rates reflect the proportion of individuals in a given population (e.g., members of a particular managed behavioral health care plan) that use specialty mental health and/or substance abuse services in 1 year.

[7] This phrase has many additional dimensions and meanings to consumers, health care providers, and health services researchers. These include (a) waiting time for emergency, urgent, and routine initial and followup appointments; (b) telephone access, including call pick-up times and call abandonment rates; (c) access to a continuum of services, including treatment in the least restrictive setting; (d) access to providers from a full range of mental health disciplines; (e) choice of individual provider; (f) geographic access; and (g) access to culturally competent treatment.

Current incentives both within and outside managed care generally do not encourage an emphasis on quality of care. Nonetheless, some managed mental health systems recognize the potential uses of quality assessment of their services. These include monitoring and assuring quality of care to public and private oversight organizations; developing programs to improve services or outcomes from systematic empirical evaluation; and permitting reward on the basis of quality and performance, not simply cost (Kane et al., 1994, 1995; Institute of Medicine, 1997; President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1997). In the public sector, the Center for Mental Health Services (CMHS), in conjunction with the Mental Health Statistics Improvement Program, has developed a Consumer-Oriented Report Card. Designed to obtain a consumer perspective on access, appropriateness, prevention, and outcome, it is being tested in 40 states under CMHS grant support.

Efforts are ongoing within managed behavioral health systems to develop quality-reporting systems based on existing administrative claims data, which measure aspects of the process of care as well as some clinical outcome data (American Managed Behavioral Healthcare Association, 1995; American College of Mental Health Administrators, 1997; National Committee for Quality Assurance, 1997).

The first comparative study of quality indicators within the managed behavioral health care industry (Frank & Shore, 1996) has revealed very diverse practices. For example, across the responding companies, expected outpatient followup visits within 30 days after hospital discharge for depression occurred among 92 percent of patients in one plan, but only 39 percent in another. One indicator of inadequate hospital treatment or discharge planning is rapid hospital readmission after discharge—an event that occurred in 2 percent to 41 percent of discharges. Another indicator of quality is the proportion of patients with schizophrenia who received a minimum of four medication visits per year; this figure ranged from 15 percent to 97 percent. Measures of access (treated prevalence rates) also varied widely. Although methodological problems probably contribute to the variation among companies, these data raise concerns about real differences in quality among managed behavioral health care companies. They also underscore the need to improve quality measurement.

In a more positive vein, investigators recently found that rates of readmission after hospital discharge were not adversely affected by the 1993 transition to a managed behavioral health carve-out for Massachusetts state employees. In fact, the proportion of cases receiving outpatient followup (within 15 or 30 days) actually increased for patients with major depressive disorder, despite substantial reductions in inpatient utilization and costs. However, because the study was based on the plan's administrative claims data, only limited conclusions could be made about the quality of care provided (Merrick, 1997).

Clinical outcome data systems, although more expensive and complicated than administrative data systems, have much greater potential for evaluating how programs and practices actually affect patient outcomes. Several managed care companies are currently testing the feasibility of implementing systemwide collection of clinical outcome data, to be managed through newly developed comprehensive clinical quality information systems (Goldman, 1997; Goldman et al., 1998).

Another way to measure quality takes into account outcomes outside the mental health specialty sector. Two recent studies suggest that when management and financial incentives limit access to mental health care or encourage a shift to general health care services for mental health care, disability may increase and work performance decline (Rosenheck et al., 1999; Salkever, 1998). These losses to employers may well offset management-based savings in mental health specialty costs. Findings such as these raise concern about the use of shortsighted cost-cutting measures that may contribute to less appropriate and less effective treatment, reduced work function, and no net economic benefits.

Many of the administrative techniques used in managed care (such as case management, utilization review, and implementation of standardized criteria) have the potential to improve the quality of care by enhancing adherence to professional consensus treatment guidelines (Berndt et al., 1998) and possibly improving patient outcomes (Katon et al., 1997). However, little is known about what happens when management is introduced into service systems in combination with high cost-sharing (often the case with non-parity mental health benefits) (Burnam & Escarce, 1999). These combined limitations on services may seriously inhibit the provision of full and necessary treatment and lower the quality of care. The differential impact on service use on the basis of gender or other sociocultural factors is unknown.

In summary, managed behavioral health plans differ considerably in their access and other aspects of quality in mental health care. Current practices often provide little incentive to improve quality. There is, however, some evidence that access and quality can be maintained or improved after managed care is introduced (Merrick, 1997). This is particularly important because some evidence suggests that limitations in mental health access affect people's well-being and result in decreases in work performance, increased absenteeism, and increased use of medical services (Rosenheck et al., 1999). Outcome assessments which focus on functional improvements are particularly important in the mental health area because of the ease with which management practices have been able to reduce treatment intensity and cost of mental health services.

Toward Parity in Coverage of Mental Health Care

"Parity" refers to the effort to treat mental health financing on the same basis as financing for general health services. In recent years advocates have repeatedly tried to expand mental health coverage—in the face of cost-containment policies that have been widespread since the 1980s. Parity legislation is an effort to address at once both the adverse selection problem and the fairness problem associated with moral hazard. The fundamental motivation behind parity legislation is the desire to cover mental illness on the same basis as somatic illness, that is, to cover mental illness fairly. A parity mandate requires all insurers in a market to offer the same coverage, equivalent to the coverage for all other disorders. The potential ability of managed care to control costs (through utilization management of moral hazard) without limiting benefits makes a parity mandate more affordable than under a fee-for-service system.

Managed care coupled with parity laws offers opportunities for focused cost control by eliminating moral hazard without unfairly restricting coverage through arbitrary limits or cost-sharing and by controlling adverse selection. However, continued use of unnecessary limits or overly aggressive management may lead to undertreatment or to restricted access to services and plans.

Benefit Restrictions and Parity

As noted above, mental health benefits are often restricted through greater limits on their use or by imposing greater cost-sharing than for other health services. Despite both the cost-controlling impact of managed care and advocacy to expand benefits, inequitable limits continue to be applied to mental health services. Parity legislation in the states and Federal government has attempted to redress this inequity.

In 1997, the most common insurance restriction was an annual limit on inpatient days; annual or lifetime limits were used somewhat less. Higher cost-sharing was used by the smallest percentage, with the use of separate deductibles almost nonexistent on inpatient mental health benefits. For outpatient mental health services, a quarter of the most prevalent plans had no special limitations (Buck et al., 1999). Unlike the situation for inpatient services, there was no marked preference for the use of any particular type of limitation for outpatient services.

Mental health benefits are significantly restricted when special limitations are employed. Maximum lifetime limits for both inpatient and outpatient services were typically only $25,000. In some extreme cases, annual limits were only $5,000 for inpatient care and $2,000 for outpatient care. Day limits remained at the traditional limit of 30 inpatient days. However, the median limit on outpatient visits, traditionally 20, reached 25 in 1997 (Buck et al., 1999)

Studies show that the gap in insurance coverage between mental health and other health services has been getting wider. One study found that the proportion of employees with coverage for mental health care increased from 1991 to 1994 (Jensen et al., 1998). However, more have multiple limits on their benefits, partly due to the increased use of managed care. Another study found that while health care costs per employee grew from 1989 to 1995, behavioral health care costs decreased, both absolutely and as a share of employers' total medical plan costs (Buck & Umland, 1997).

A report by the HayGroup (1998) on changes in the health plans of medium and large employers provides more recent evidence for these trends. Between 1988 and 1997, the proportion of such plans with day limits on inpatient psychiatric care increased from 38 percent to 57 percent, whereas the proportion of plans with outpatient visit limits rose from 26 percent to 48 percent. On the basis of this and other information, the HayGroup estimated that the value of behavioral health care benefits within the surveyed plans decreased from 6.1 percent to 3.1 percent from 1988 to 1997 as a proportion of the value of the total health benefit (HayGroup, 1998).

Extensive limits on mental health benefits can create major financial burdens for patients and their families. One economic study modeled the out-of-pocket burden that families face under existing mental health coverage using different mental health expense scenarios (Zuvekas et al., 1998). For a family with mental health treatment expenses of $35,000 a year, the average out-of-pocket burden is $12,000; for those with $60,000 in mental health expenses a year, the burden averages $27,000. This is in stark contrast to the out-of-pocket expense of only $1,500 and $1,800, respectively, that a family would pay for medical/surgical treatment.

Legislative Trends Affecting Parity in Mental Health Insurance Coverage

Federal legislative efforts to achieve parity in mental health insurance coverage date from the 1970s and have continued through to present times. However, a major parity initiative was included in the failed 1994 Health Security Act (the Clinton Administration's health care reform proposal). Although national health care reform stalled, the drive for mental health parity continued, culminating in passage of the Mental Health Parity Act in 1996. Implemented in 1998, this legislation focused on only one aspect of the inequities in mental health insurance coverage: "catastrophic" benefits. It prohibited the use of lifetime and annual limits on coverage that were different for mental and somatic illnesses. As Federal legislation, it included within its mandate some of the Nation's largest companies that are self-insured and otherwise exempted from state parity laws because of the Employment Retirement Income Security Act. Although it was seen as an important first substantive step and rhetorical victory for mental health advocacy, the Parity Act was limited in a number of important ways. Companies with fewer than 50 employees or which offered no mental health benefit were exempt from provisions of the law. The parity provisions did not apply to other forms of benefit limits, such as per episode limits on length of stay or visit limits, or copayments or deductibles, and they did not include substance abuse treatment. In addition, insurers who experienced more than a 1 percent rise in premium as a result of implementing parity could apply for an exemption. Despite these limitations, Federal parity legislation put mental health coverage concerns "on the map" for policymakers and demonstrated an unprecedented concern to redress inequities in coverage (Goldman, 1997).

State efforts at parity legislation paralleled those at the Federal level. During the past decade, a growing number of states have implemented parity (Hennessy & Stephens, 1997; National Advisory Mental Health Council, 1998; SAMHSA, 1999). Some (e.g., Texas) target their parity legislation narrowly to include only people with severe mental disorders; others use a broader definition of mental illness for parity coverage (e.g., Maryland) and include, in some cases, substance abuse. Some states (e.g., Maryland) focus on a broad range of insured populations; others focus only on a single population (e.g., Texas state employees) (National Alliance for the Mentally Ill, 1999).

Until recently, efforts to achieve parity in insurance coverage for the treatment of mental disorders were hampered by limited information on the effects of such mandates. This led to wide variations in estimates of the costs of implementing such laws. For example, past estimates of the increase in premium costs of full parity in proposed federal legislation have ranged from 3 percent to more than 10 percent (Sing et al., 1998).

Recent analyses of the experience with state and Federal parity laws have begun to provide a firmer basis for such estimates. These studies indicate that implementing parity laws is not as expensive as some have suggested.

Case studies of five states that had a parity law for at least a year revealed a small effect on premiums—at most a change of a few percent, plus or minus. Further, employers did not attempt to avoid the laws by becoming self-insured or by passing on costs to employees (Sing et al., 1998). Separate studies of laws in Texas, Maryland, and North Carolina have shown that costs actually declined after parity was introduced where legislation coincided with the introduction of managed care. In general, the number of users increased, with lower average expenditures per user. There is no evidence on the appropriateness of treatment delivered following the introduction of parity laws (National Advisory Mental Health Council, 1998). Similar findings come from case studies of private insurance plans that have provided generous mental health benefits (Goldman et al., 1998) and of plans that have switched to carve-out managed care (Ma & McGuire, 1998; Sturm et al., 1999).

Some evidence also exists of the effects of the Federal Mental Health Parity Act, which went into effect in 1998. Under that law, group health plans providing mental health benefits may not impose a lower lifetime or annual dollar limit on mental health benefits than exists for medical/surgical benefits. A national survey of employers conducted after the Act went into effect found that while mid- to large-size companies made some reductions in benefits and added cost-sharing, small companies (the majority of companies in the country) did not make compensatory changes to their benefits. This was because they judged that the projected costs were minimal or nonexistent (SAMHSA, 1999). Additional evidence that the law has resulted in minimal added expense comes from exemptions that may be granted if a plan experiences a cost increase of at least 1 percent because of the law. In the first year of the law's implementation, only a few plans nationwide had requested such an exemption (SAMHSA, 1999).

In summary, evidence of the effects of parity laws shows that their costs are minimal. Introducing or increasing the level of managed care can significantly limit or even reduce the costs of implementing such laws. Within carve-out forms of managed care, research generally shows that parity results in less than a 1 percent increase in total health care costs. In plans that have not previously used managed care, introducing parity simultaneously with managed care can result in an actual reduction in such costs.

Conclusions

In the United States in the late 20th century, research-based capabilities to identify, treat, and, in some instances, prevent mental disorders are outpacing the capacities of the service system the Nation has in place to deliver mental health care to all who would benefit from it. Approximately 10 percent of children and adults receive mental health services from mental health specialists or general medical providers in a given year. Approximately one in six adults, and one in five children, obtain mental health services either from health care providers, the clergy, social service agencies, or schools in a given year.

Chapter 6 discusses the organization and financing of mental health services. The chapter provides an overview of the current system of mental health services, describing where people get care and how they use services. The chapter then presents information on the costs of care and trends in spending. Only within recent decades, in the face of concerns about discriminatory policies in mental health financing, have the dynamics of insurance financing become a significant issue in the mental health field. In particular, policies that have emphasized cost containment have ushered in managed care. Intensive research currently is addressing both positive and adverse effects of managed care on access and quality, generating information that will guard against untoward consequences of aggressive cost-containment policies. Inequities in insurance coverage for mental health and general medical care—the product of decades of stigma and discrimination—have prompted efforts to correct them through legislation designed to produce financing changes and create parity. Parity calls for equality between mental health and other health coverage.

1. Epidemiologic surveys indicate that one in five Americans has a mental disorder in any one year.
2. Fifteen percent of the adult population use some form of mental health service during the year. Eight percent have a mental disorder; 7 percent have a mental health problem.
3. Twenty-one percent of children ages 9 to 17 receive mental health services in a year.
4. The U.S. mental health service system is complex and connects many sectors (public–private, specialty–general health, health–social welfare, housing, criminal justice, and education). As a result, care may become organizationally fragmented, creating barriers to access. The system is also financed from many funding streams, adding to the complexity, given sometimes competing incentives between funding sources.
5. In 1996, the direct treatment of mental disorders, substance abuse, and Alzheimer's disease cost the Nation $99 billion; direct costs for mental disorders alone totaled $69 billion. In 1990, indirect costs for mental disorders alone totaled $79 billion.
6. Historically, financial barriers to mental health services have been attributable to a variety of economic forces and concerns (e.g., market failure, adverse selection, moral hazard, and public provision). This has accounted for differential resource allocation rules for financing mental health services.
    a. "Parity" legislation has been a partial solution to this set of problems.
    b. Implementing parity has resulted in negligible cost increases where the care has been managed.
7. In recent years, managed care has begun to introduce dramatic changes into the organization and financing of health and mental health services.
8. Trends indicate that in some segments of the private sector per capita mental health expenditures have declined much faster than they have for other conditions.
9. There is little direct evidence of problems with quality in well-implemented managed care programs. The risk for more impaired populations and children remains a serious concern.
10. An array of quality monitoring and quality improvement mechanisms has been developed, although incentives for their full implementation have yet to emerge. In addition, competition on the basis of quality is only beginning in the managed care industry.
11. There is increasing concern about consumer satisfaction and consumers' rights. A Consumers Bill of Rights has been developed and implemented in Federal Employee Health Benefit Plans, with broader legislation currently pending in the Congress.

Appendix 6-A: Quality and Consumers' Rights

The Federal government's concern with quality in the Nation's health care system was expressed in President Clinton's charge to the Advisory Commission on Consumer Protection and Quality in the Health Care Industry (March 26, 1997) "to recommend such measures as may be necessary to promote and assure health care quality and value and protect consumers and workers in the health care system." In November 1997 the Commission recommended a Consumer Bill of Rights and Responsibilities (President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1997).

The Consumer Bill of Rights and Responsibilities (Bill of Rights) is intended to meet three major goals:

- Strengthen consumer confidence by assuring that the health care system is fair and responsive to consumers' needs; it gives consumers credible and effective mechanisms for addressing their concerns and encourages them to take an active role in improving and assuring their health.
- Reaffirm the importance of a strong relationship between consumers and their health care professionals.
- Underscore the critical role of consumers in safeguarding their own health by establishing both rights and responsibilities for all participants in improving health status.

The Bill of Rights addresses a number of issues that are particularly relevant to mental health care:

- Information disclosure of comparable measures of quality and consumer satisfaction from health plans, professionals, and facilities;
- Direct access to specialists of choice for consumers with complex or serious medical conditions who require frequent specialty care;
- Authorization, when required, for an adequate number of visits under an approved treatment plan;
- Vulnerable groups, including individuals with mental disabilities, require special attention by decisionmakers to protect their health coverage and quality of care;
- Confidentiality protections for sensitive services, such as mental health and substance abuse services, provided by health plans, providers, employers, and purchasers to safeguard against improper use or release of individually identifiable information.
- To move the mental health care system from a focus on providers to a focus on consumers, future care systems and quality tools will need to reflect person-centered values. This nascent trend is driven both by the consumer movement in American society and by a strong focus on consumer rights in a managed care environment. First steps include the voluntary adoption of the principles of the Consumer Bill of Rights by Federal agencies and passage of legislation requiring their national implementation.

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CHAPTER 7

CONFIDENTIALITY OF MENTAL HEALTH INFORMATION: ETHICAL, LEGAL, AND POLICY ISSUES

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CHAPTER 7

CONFIDENTIALITY OF MENTAL HEALTH INFORMATION: ETHICAL, LEGAL, AND POLICY ISSUES

Effective psychotherapy. . . depends upon an atmosphere of confidence and trust in which the patient is willing to make a frank and complete disclosure of facts, emotions, memories, and fears. Because of the sensitive nature of the problems for which individuals consult psychotherapists, disclosure of confidential communications made during counseling sessions may cause embarrassment or disgrace. For this reason, the mere possibility of disclosure may impede development of the confidential relationship necessary for successful treatment.

This ringing endorsement of the importance of confidentiality in the provision of mental health treatment comes from the U.S. Supreme Court (*Jaffee v. Redmond*, 1996). The Court's language, in a decision creating a psychotherapist privilege in Federal court, appears to leave little doubt that there is broad legal protection for the principle of confidentiality. Public opinion polls also show widespread support for the privacy of health care information: 85 percent of those responding to one survey characterized protecting the privacy of medical records as essential or very important (Peck, 1994).

Yet the reality is much more complex. State and Federal laws do protect the confidentiality of health care information, including information created in providing mental health and substance abuse treatment. However, these laws have numerous exceptions, are inconsistent from state to state, and, in the opinion of many experts, provide less protection of confidentiality than is warranted.

In addition, changes in the health care industry, and advances in technology, have created new concerns regarding the privacy of health care information. Health care increasingly is delivered and paid for by for-profit corporations with business in many states. This shift has several relevant consequences. First, individual health care information may be held and disseminated far beyond the office of the practitioner providing care. Second, cost containment concerns have resulted in the emergence of a variety of techniques that depend on third-party review of a practitioner's judgment that an individual should receive care, reviews that have resulted in increased demands for patient-specific information before care is approved. In addition, private health care information may be distributed for the purpose of marketing commercial products, such as pharmaceuticals, a growing business that many believe constitutes an improper use of such information (Jeffords, 1997; O'Harrow, 1998). Finally, private health information is used to create much larger databases, for various purposes including treatment and research, thereby increasing the number of people with access to such information.

Technology also has emerged as a major issue in privacy debates. The ultimate impact of technology is not yet clear. One leading expert on the privacy of health care information asked whether technology would help or hinder the protection of health care privacy, responded that the answer was yes and no (Gellman, in press). On the one hand, new technologies can support, and in some cases make possible, the changes that have transformed the health care industry. The "health information technology industry" in 1997 sold approximately $15 billion of products to health care organizations, including medical business decision-support software, data warehousing, clinical expert systems, and electronic medical record systems designed to support large health care enterprises (Kleinke, 1998). There also have been ongoing efforts to create computer-based patient records for several years (Dick & Stean, 1991). Such records in many ways can be more secure than paper records through various mechanisms, for example, by restricting access to designated users. Yet much of the same technology raises concerns about privacy, because of its capacity to store and disseminate rapidly to multiple users personal information that many individuals would prefer remain private. If the myriad needs of the health care system could be met by using only data stripped of patient-specific information, many concerns about privacy might be ameliorated. However, data that identify the individual are still considered necessary for many purposes, including the administration of payment systems and fraud investigations. This has led some to conclude that the ultimate question when patient-specific data are transported and used outside of the clinical context is security of the data (Moran, 1998).

Congress, in an effort to respond to growing public concern over health care information privacy, has committed the Federal government to the creation of a national confidentiality standard by 2000. Congress also has directed the Secretary of Health and Human Services to produce recommendations for simplifying and standardizing requirements for the electronic transmission of health information (Health Insurance Portability and Accountability Act, 1996). The purpose is to improve the effectiveness and efficiency of the health care system (Gellman, 2000). It is not yet clear, given the complexities of the issues, that the deadline for a national privacy standard will be met. However, it is clear that the confidentiality of health care information has emerged as a core issue in recent years, as concerns regarding the accessibility of health care information and its uses have risen.

Chapter Overview

This section of the report discusses the values underlying confidentiality, its importance in individual decisions to seek mental health treatment, the legal framework governing confidentiality and potential problems with that framework, and policy issues that must be addressed by those concerned with the confidentiality of mental health and substance abuse information. Although the current debate regarding Federal standards is not presented in great detail, it is referred to when appropriate to provide context for the broader discussion.

Ethical Issues About Confidentiality

Each profession that provides mental health treatment embraces confidentiality as a core ethical principle. For example, the Code of Ethics of the American Medical Association (AMA) states that "a physician . . . shall safeguard a patient's confidences within the restraints of the law" (American Medical Association [AMA], 1996). The AMA more recently has observed that "patients have a basic right to privacy of their medical information and records. . .patients' privacy should be honored unless waived by the patient in a meaningful way, or in rare instances of strongly countervailing public interest" (AMA, 1998). The Ethical Principles of Psychologists state that "psychologists have a primary obligation and take reasonable precautions to respect . . . confidentiality rights" (American Psychological Association, 1992). (See also, American Managed Behavioral Healthcare Association, 1998; American Psychiatric Association, 1998; National Alliance for the Mentally Ill, 1998).

While the importance of confidentiality as an ethical principle is evident from these statements, it is also clear that confidentiality is not an absolute value. The AMA's 1996 statement qualifies the principle of confidentiality by observing that it is to be protected "within the restraints of the law." The American Psychological Association provides exceptions as well, noting for example that disclosure of otherwise confidential information is permissible "where permitted by law for a valid purpose, such as . . .(3) to protect the patient or client from harm" (Ethical Principles of Psychologists and Code of Conduct, 5.05). As the discussion below suggests, the law creates many circumstances in which confidentiality may or must be breached. At the same time, legal principles reflect broader values, and so there is often significant disagreement about the exceptions to confidentiality that the law permits or requires.

It is also important to note at the outset that the right to confidentiality belongs to the person receiving services (Campbell, 2000). The ethical codes of the various professions, and most confidentiality laws, obligate professionals to take steps to protect confidentiality. However, in general, the right to confidentiality belongs to the client; the right to waive confidentiality also is the client's, although there are situations in which the provider of treatment has no choice under the law but to disclose.

Values Underlying Confidentiality

The principle of confidentiality is designed to advance certain values. These include reducing the stigma and discrimination associated with seeking and receiving mental health treatment, fostering trust in the treatment relationship, ensuring individuals privacy in their health care decisions, and furthering individual autonomy in health care decisionmaking.

Reducing Stigma

There are certain illnesses that often evoke public unease and on occasion overt discrimination. For example, in the past, cancer was often not discussed; in fact, physicians often chose not to tell patients that they had diagnosed cancer. In recent years, individuals with AIDS have often faced discrimination. Mental illness has often fallen into this category as well. For years, the stigma and discrimination associated with mental illness were reinforced by laws that stripped people of their legal rights upon admission to a psychiatric hospital, and by social attitudes that often equated mental illness with potential violence. While many of the legal rules that reinforced discrimination have been removed, public attitudes regarding mental illness continue to vary. In an effort to reduce the risk of stigma and the discrimination that often results, confidentiality laws seek to protect both the fact that an individual has sought mental health treatment as well as the disclosures that are made during treatment.

Fostering Trust

Confidentiality generally is considered to be a cornerstone of a doctor-patient relationship (Dierks, 1993). Many psychotherapists assume that mental health treatment is most likely to be successful only if the client has a trusting relationship with the clinician (Sharkin, 1995). The Supreme Court language quoted at the beginning of this section reflects the same assumption. While the research findings on this subject are somewhat mixed (see discussion below), it is beyond dispute that many individuals in seeking treatment for mental illness reveal much of their private selves. It seems reasonable to assume that for many people, trust that their privacy will not be intruded upon beyond the confines of the clinical relationship is an important element in permitting unguarded exchanges during treatment. Concerns regarding confidentiality may cause individuals to take steps to protect themselves from unwanted disclosures in other ways that carry their own costs. For example, an individual may decide to pay for his or her own care, withhold certain types of sensitive information during treatment, or avoid seeking care.

Protecting Privacy

The law has given considerable attention in the last 3 decades to the idea that people have a right to privacy in making decisions regarding their health care. While the legal right to privacy has been discussed and applied most often in the context of decisions involving procreation and decisions at the end of life, the general principle that the value of privacy is important to mental health treatment is not disputed.

Competent individuals, or in the case of minor children, their parents or legal guardians, have a right to self-determination in deciding to seek or forego health care, including mental health or substance abuse treatment. There are exceptions, for example, the use of involuntary civil commitment or court-ordered treatment. However, the general trend has been to expand autonomy in health care decisionmaking. Two ethical and legal principles are important anchors to the principle of autonomy. The first, informed consent, assumes that the better informed an individual is, the better equipped he or she is to make health care decisions. The second, confidentiality, is considered to be particularly important in the context of mental health treatment. This is because of the assumption that an absence of confidentiality may make a person less likely to seek treatment.

Research on Confidentiality and Mental Health Treatment

The values that underlie confidentiality in large part assume that people will be less likely to seek needed help (Corcoran & Winsalde, 1994) and, once in treatment, less likely to disclose sensitive information about themselves if they believe that the information may be disseminated outside the treatment relationship. Available research supports these assumptions. For example, in one study, individuals receiving psychotherapy placed a high value on the importance of confidentiality to the therapeutic relationship, as did a matched group of hospital employees (McGuire et al., 1985). Parents of children in psychotherapy reported that confidentiality was an important issue that needed to be discussed in the context of informed consent processes (Jensen et al., 1991). Another study suggests that concerns regarding stigma and confidentiality were factors in decisions by people with dual diagnoses (psychiatric illness and substance abuse disorder) to seek treatment from the community mental health system (Howland, 1995). Yet another study reports that the decision of therapists to seek or not seek treatment was influenced, among other things, by concerns regarding confidentiality (Norman & Rosvall, 1994). In the context of drug testing, the degree to which confidentiality was protected influenced the attitudes of those who had been ordered into drug testing regarding the seeking of employment (Sujak et al., 1995).

Subjects who were told that confidentiality was absolute reported that they were more willing to disclose information about themselves than individuals who were told that confidentiality was limited (Nowell & Spruill, 1993). Confidentiality, of course, is not absolute, and so the impact on individuals in treatment of various limits on confidentiality is an important question. This was explored in one of the few confidentiality studies to use as research subjects people actually in treatment (rather than students simulating the role of patient). Taube and Elwork (1990) found that patient self-disclosure was influenced in large measure by how informed the patient was about confidentiality law and by how consequential to the patient the legal limits on confidentiality were in his or her particular circumstances. Roback and Shelton (1995), noting that some studies suggested that perceived limitations on confidentiality did not deter patients from self-disclosing, also noted that as persons perceived themselves at risk for serious sociolegal consequences, being informed that certain disclosures would result in mandatory reporting did limit self-disclosing.

Finally, one of the most recent studies of this subject, which used clients and college students as subjects for the research, concluded that subjects were less candid with a therapist if they understood that information regarding their treatment was to be disclosed to a third party for case utilization review (Kremer & Gesten, 1998). As a result, another observer concluded that "psychiatric treatment is often paid for by patients out-of-pocket, precisely to avoid creating a record over which a patient has little or no control" (Alpert, 1998, p. 89).

Surveys of the general public also indicate that privacy of health care information is a major concern. For example, 27 percent of the respondents to a 1993 Harris survey believed that health care information about them had been improperly disclosed. 11 percent previously had decided to not file an insurance claim because of privacy concerns, and 7 percent had decided to forego care because of concern that information that would be generated in care might harm their employment possibilities or other opportunities (Louis Harris & Associates, 1993).

These findings suggest a dilemma for individuals who may wish to pursue treatment for mental illness and for treatment providers. All available data indicate that confidentiality of health care information is a significant concern for individuals. The evidence also indicates that people may become less willing to make disclosures during treatment if they know that information will be disseminated beyond the treatment relationship. At the same time, the caregiver is ethically obligated to disclose to the client the limits on confidentiality: A failure to reveal the limits of confidentiality seriously threatens the therapeutic relationship and the provider's credibility. As a result, treatment may be compromised, and the patient may terminate treatment prematurely (Kremer & Gesten, 1998).

In short, available research supports the conclusion that strong confidentiality laws are critical in creating assurances for individuals seeking mental health treatment and thereby increasing willingness to participate in treatment to the degree necessary to achieve successful outcomes. However, the present legal framework does not provide strong, consistent protection of confidentiality in many instances.

It is important to note that additional factors may contribute to concern that confidentiality may be breached and, in turn, an unwillingness on the part of consumers to disclose or share information. In many instances, these factors cannot be addressed through stronger legal protections alone. In given clinical settings, for example, concern may stem from the existence of crowded or open facilities, frequent changes in clinical staff, language differences, cultural considerations, and other constraints that would limit establishing a trusting therapeutic relationship. In addition, individuals may not wish to disclose information regarding "pre-existing conditions" for fear it may result in a loss of insurance coverage as well as privacy.

Current State of Confidentiality Law

One expert has described the current law governing the confidentiality of health care information as a "crazy quilt of Federal and state constitutional, statutory, regulatory and case law" that "erodes personal privacy and forms a serious barrier to administrative simplification" (Waller, 1995, p. 44). This aptly describes the current legal framework for the confidentiality of mental health and substance abuse information as well.

There is at present no national standard for the confidentiality of health care information in general or mental health information in particular. Rather, each state has laws that establish confidentiality rules and exceptions. In response to a serious public policy concern that the criminal justice ramifications of use of illegal substances would significantly deter individuals from seeking substance abuse treatment, a national standard governing the confidentiality of substance abuse treatment information was codified. However, there often are significant differences among states and between the state and Federal requirements, which can create problems for the administrators of health care plans and for those providing treatment for people with co-occurring mental illness and substance abuse disorders.

Overview of State Confidentiality Laws

As noted, nearly all states have discrete statutes addressing the confidentiality of mental health records and information. In a handful of states, a general law applicable to all health care information applies. In some states, the mental health confidentiality statute applies only to information gathered when a state facility provides treatment; in others, it applies to mental health treatment regardless of the auspice of care.

One common criticism of health care information laws generally is that they apply primarily to information gathered in the course of treatment and in the possession of the caregiver. This means that different standards apply to the distribution of information held by others not party to the treatment relationship. This observation fairly characterizes most state mental health laws as well. The focus of the laws tends to be upon the clinical relationship, and often what happens to information once it is disseminated beyond the clinical relationship is unaddressed. Many of the reform proposals advanced in recent years would apply confidentiality rules to other parties that come into possession of protected information, although the proposals vary regarding application of a national standard to employers, schools, correctional facilities, and other settings in which a significant volume of health care is provided. In addition, the proposals vary regarding the question of whether the individual has a legal right to consent to disclosures beyond the clinical relationship: How this question is resolved will determine in large measure whether individuals in the role of patient believe that confidentiality protections are strong enough to warrant seeking treatment.

While the various reform proposals differ in detail, few dispute the need to extend the obligation to protect confidentiality to other parties. In the early 1980s, one expert found that between 25 and 100 people had access to an individual inpatient record (Siegler, 1982), a number that has grown in recent years. In addition, as health care delivery and payment have become increasingly complex and as provider networks rather than individual practitioners increasingly provide care, the number of people who may come into possession of health care information continues to expand. One observer describes three "zones" of users of personal health care information. "Zone one" users are involved in direct patient care, while "zone two" users are involved in support and administrative activities like payment and quality of care reviews. "Zone three" users include public health agencies, social welfare agencies, researchers, and direct marketing firms (Westin, 1993). Some of these parties traditionally have had ready access to health care information; others, for example, utilization review managers and direct marketing firms, are comparatively new to health care. Whether a party that has access to information *should* have access to that information is a separate question that lies at the heart of much of the debate about confidentiality.

Exceptions to Confidentiality

Each state law creates exceptions to confidentiality. While state laws vary regarding the number and type of exceptions permitted, the most common exceptions to confidentiality are discussed briefly below. As a prefatory note, many experts assume that client consent presumptively should be required prior to most if not all disclosures, and that any waiver of confidentiality by the client must be truly informed (Campbell, 2000). However, as the discussion below suggests, many state laws permit a variety of disclosures without client consent, raising questions regarding the adequacy of these laws in protecting client confidentiality in the current environment.

Consent by the Person in Treatment

The most common exception to confidentiality is when the person who is or has been in treatment consents to the waiver of confidentiality. (For minor children, this right rests with the parents or legal guardians.) For example, the practitioner may ask that the person sign a consent form authorizing the release to the practitioner of other health care records. This reflects the fact that the right to confidentiality is designed primarily to protect the patient, not other parties, from unwanted disclosures, and that the right to waive confidentiality presumptively rests with the patient. In some instances, where confidentiality is waived, the patient nonetheless may wish to avoid release of certain information in any circumstances and direct that the provider not include in the file sensitive personal information—for example, sexual orientation or marital infidelities.

Although each state provides for waiver of confidentiality by the person in treatment, few states spell out in statute the elements of a valid consent. This is in contrast to the Federal laws on substance and alcohol treatment information, discussed below, which provide explicit details regarding the content of a valid consent.

In addition, the various reform proposals that have been introduced in Congress and elsewhere each contain criteria for consent. These typically include requirements that consent be in writing, name the individual or entity to which disclosure of information is to be made, identify the purpose or need for disclosure and the type of information to be disclosed, and state the period for which the consent is effective. However, it should be noted that the proposals differ on the question of the degree to which a person's consent to disclosure would be truly voluntary. Many of the proposals suggest that a person's treatment, or reimbursement for treatment, may depend on whether the person consents to have his or her records disclosed. This may raise questions about how "voluntary" such consent is, in fact, given that access to the services sought may be contingent upon agreeing to the release of information divulged during treatment.

Disclosure to the Client

Many, though not all, state laws provide that individuals have a right of access to health care records containing information about them. Some provide that a clinician may restrict access to the record, if in the clinician's judgment, access would cause harm to the client. Some statutes also provide that a clinician may restrict access to particular parts of the record if access might harm the client or if third parties provided information with the expectation that it would be held in confidence. Some experts have suggested that limiting client access undercuts the principle that information contained in the record belongs first to the client (Campbell, 2000). Each reform proposal articulated to date provides for access by an individual to health care information. These proposals assume that access is necessary both so that the individual is fully informed regarding his or her health care and so that the individual can correct information that might be erroneous. Generally, for minor children, parents have the right of access. Some experts have suggested that in the case of children, even in instances in which the parents or guardians control the information, there should be a right for the child to establish a "zone of privacy" for certain "intimate" information. Such information could not be accessed by responsible adults except when the clinician determines that it indicates imminent danger of harm to self or others (Melton, 2000).

Disclosure to Other Providers

An important question in an era in which networks of providers provide increasing amounts of care is whether and how confidentiality laws permit disclosure to other caregivers. The majority of states that address this issue typically provide for disclosure to others involved in providing care. Some states require consent before information can be disclosed, although the majority of state laws that address the issue do not. Few states address the question of information exchange within a network of providers.

Some proposals before Congress would permit disclosure of information to other care providers without requiring consent. Others would require consent prior to any disclosure. At least one presumptively would permit disclosure, but give the individual the opportunity to "opt out" of a particular disclosure. As noted earlier, conditioning access to treatment (or to reimbursement) on a waiver of confidentiality calls into question the voluntariness of the waiver.

Disclosure to Payers

Many states have provisions in their mental health confidentiality laws that permit disclosure of otherwise confidential information as necessary to obtain reimbursement or other financial assistance for the person in treatment. Most of these statutes were written before the emergence of managed care and third-party utilization review. Therefore, most state laws that create this exception to confidentiality impose few if any limitations on the type or amount of information that can be disclosed to obtain reimbursement, and most do not explicitly require consent prior to disclosure. There are exceptions that might prove useful models to other jurisdictions. For example, New Jersey restricts disclosure of information from licensed psychologists to third-party payers. The statute permits disclosure only if the client consents, and if disclosure is limited to: (1) administrative information; (2) diagnostic information; (3) the legal status of the patient; (4) the reason for continuing psychological services; (5) assessment of the client's current level of functioning and level of distress; and (6) a prognosis, limited to the minimal time treatment might continue (New Jersey Statutes). The

Commonwealth of Massachusetts also limits disclosures to third-party payers of mental health information (Massachusetts Annotated Laws).

As noted, the proposals that have been made to date to create a national standard for the confidentiality of health care information differ in how they treat disclosures to other providers and payers. Some proposals would require patient consent prior to any disclosure. Others would presume consent. Still others would permit the individual to "opt out" of specific disclosures. The last would require that individuals be given the names of providers and payers that might be provided access to information; the individual could then decline permission to provide information to specific payers or providers.

The question of how much information should be made available to third-party reviewers is a contentious one. As the research described earlier suggests, the willingness to self-disclose, or to participate in treatment, appears to be contingent at least in part on the strength of confidentiality provisions. As the amount and sensitivity of information made available to third- party reviewers increases, a corresponding decrease on the part of some individuals to seek treatment is likely.

Disclosure of Information to Families

An issue of some controversy in mental health is whether families should be provided information regarding their adult child in certain circumstances. As a general rule, access to information in circumstances involving minor children is provided to parents or the legal guardian of the child, until the child attains the age of majority or an age at which the child is permitted under state law to make his or her own treatment decisions.

Some states provide that parents acting in the role of caregiver may be given information, usually limited to diagnosis, prognosis, and information regarding treatment, specifically medications. Of those states with these or similar provisions, some permit the disclosure of this information without the consent of the individual, while others require consent, with some providing for administrative review if consent is not given. All of the reform proposals that have been introduced before Congress provide for the disclosure of limited information regarding an individual's current health status to family or next of kin. Consent generally is not required, although most provide the patient with the opportunity to request that information not be provided in such circumstances. It should be noted that in the context of mental health treatment, there is disagreement regarding this issue, particularly on the issue of prior consent. Family advocates often take the position that a family in a caregiving role should have access to some types of information whether or not the individual specifically has consented to the disclosure, because it is necessary to play a caregiving role (Lefly, 2000). Advocates for consumer-recipients often argue that consent should be required, because the right to confidentiality belongs to the recipient of services, and because there may be intrafamily conflicts that could be exacerbated by the release of information to family members.

Oversight and Public Health Reporting

All states have provisions that allow entities with oversight responsibilities to have access to medical records without client consent. Similarly, states mandate that certain types of information be made available to public health officials for various public health purposes, for example, the reporting of infectious diseases or the prescription of particular types of medication. The various reform proposals would do little to change this type of reporting, although at least one would create a preference for the use of records in which personal identifying information has been deleted.

Research

The confidentiality of individually identifiable information gathered in the course of conducting research can be protected from compelled disclosure by obtaining federally issued "certificates of confidentiality." These certificates are issued through the Department of Health and Human Services upon application by the researcher for research which involves the collection of specific types of sensitive information judged necessary to achieve the research objectives. The importance of the protection against disclosure afforded by Federal "certificates of confidentiality" increases as research expands its traditional boundaries to include genetic information of uncertain/evolving clinical relevance. An individual may voluntarily consent to the disclosure of information obtained in the course of protected research. In addition, the researcher may identify certain specific information which may be voluntarily disclosed in participants' consent forms.

States that address access to confidential information for research purposes generally provide for access without consent if it is impracticable to obtain individual consent and the research has been approved by the agency with approval authority under the state law. It should be noted that regardless of the aforementioned protections, information obtained in protected research studies, which finds its way into the participant's regular medical chart, is not covered.

Disclosure to Law Enforcement Agencies

Many state laws limit access to information regarding people with mental illness by law enforcement officials to situations in which an individual who has been hospitalized has left the hospital and not returned, or to situations in which a crime has been committed on the grounds of a treatment facility. A handful of state laws provides access for the purpose of investigating health care fraud. In contrast, most of the reform proposals designed to create a national standard provide comparatively broad access by law enforcement officials. Others would limit discovery to situations in which law enforcement could demonstrate, usually by clear and convincing evidence, that disclosure is necessary.

This is a controversial issue. Some professional and advocacy groups believe that broad access by law enforcement officials will lead to unwarranted invasions of privacy and encourage "fishing expeditions" in which material revealed during treatment becomes the basis of criminal prosecution. On the other hand, some have argued that broad access is necessary, particularly to investigate health care fraud in which the conduct of the provider rather than the client is at issue. The current Federal substance abuse laws provide for a stricter standard for access to information by law enforcement officials than is provided for in many of the proposals before Congress. This strict standard is based on the assumption that broader access would have a negative effect on the willingness of people to seek substance abuse treatment, if seeking treatment might lead to criminal prosecution. While these provisions seem to have met their intended goal of encouraging individuals to seek treatment, there is no evidence that stricter Federal standards for access to substance abuse information have impeded law enforcement efforts.

Disclosure to Protect Third Parties

In 1976, the California Supreme Court ruled that a mental health professional has an obligation to take steps to protect identified third parties whom the professional reasonably believes might be endangered by a client (Tarasoff v. Regents, 1976). This decision was criticized by a number of groups, including the American Psychiatric Association and the American Psychological Association, on the grounds that it required mental health professionals to perform a task for which they were ill-suited (that is, assess future risk) and that it would compromise confidentiality. Since the court's decision, many states, either through statute or judicial decision, have addressed this topic.

The majority of states that have done so through statute provide that a mental health professional who concludes that his or her client represents an imminent danger to an identified third party may take steps, including notifying the individual or law enforcement officials, to protect the third party without becoming liable for a breach of confidentiality. These states also typically provide that the clinician will not be liable if he or she decides not to act—rather, the statutes give the clinician discretion in deciding how to proceed.

In addition, all states permit or mandate disclosure in other situations where a third party might be at risk for harm. Child abuse and elder abuse reporting laws are examples. Most of the proposals to create a national standard permit disclosures necessary to protect an identifiable third party when the caregiver concludes that there is a risk of serious injury or death, or when disclosure is necessary to protect the patient from serious harm.

Federal Confidentiality Laws

An individual who seeks treatment for mental illness runs the risk of discrimination and invasion of privacy if information disclosed during treatment becomes known to third parties. An individual who seeks treatment for a substance use problem may reveal information that if disclosed could become the basis for criminal prosecution. The prospect of prosecution as a price of entering treatment quite clearly may create disincentives to seek treatment.

In an effort to create incentives for people with substance use and alcohol problems to seek treatment, Congress enacted perhaps the strictest confidentiality law extant. As a result, Federal law governs the confidentiality of information, obtained by federally assisted, specialized substance abuse treatment programs, which would identify a patient as receiving treatment services (42 U.S.C. 290dd-2; 42 C.F.R. 2.1, et seq.).

Disclosure of patient identifying information by federally assisted programs is permitted only in explicitly delineated circumstances. The person receiving services can waive confidentiality, but consent must be written; name the client, the program making the disclosure, and the intended recipient of the information; state the purpose of the disclosure and the information to be disclosed; be signed by the client or representative of the patient where appropriate; and state the duration of the consent and conditions under which it expires. In the absence of consent, disclosures may be made only in the circumstances permitted by the regulations. For example, information may be exchanged within the program providing services, but only to the extent necessary to provide services. In other words, information is to be exchanged even within the treatment program on a "need to know" basis. Disclosures may be made without consent to other service providers if providers have entered into a "qualified service agreement" with the treating program. This is to permit the treating program to obtain collateral services, for example, blood work, that are not performed by the program itself. Disclosures to other providers not part of a qualified service agreement can only occur with consent.

Disclosure also is permitted to law enforcement officials when there was a crime committed on the premises or against the personnel of the treatment program. Even in this case, information provided is to be limited initially to the name, address, and last known whereabouts of the individual who committed or threatened to commit a crime. Other circumstances in which disclosures are permitted without consent include medical emergencies as defined in the regulations; child abuse reports; court orders, when the court has followed procedures established in the regulations; and in criminal investigations of "extremely serious crimes" as defined in the regulations (Center for Substance Abuse Treatment, 1994). The statute and regulations do not address, and therefore do not permit, disclosures to families of clients or to payers without consent of the client.

The Federal law is generally much more detailed than any state mental health law in delineating the conditions that must be met before disclosures can occur. In addition, as this brief summary suggests, state mental health laws and the Federal alcohol and substance abuse laws differ substantively in many respects. This may create difficulties for providers caring for people with co-occurring mental illness and substance use disorders, because the provider may be operating under two quite different legal standards in considering requests for information regarding the same individual. This issue is discussed in more detail below.

Other Federal statutes have limited applicability to the confidentiality of health care information. The Privacy Act of 1974 prohibits disclosure of an individual's record without prior written consent and provides access to review, copy, and correct records. However, the Act applies only to federally operated hospitals and to research or health care institutions operated pursuant to Federal contracts, so it does not cover the vast majority of organizations and entities collecting health care information (Gostin, 1995). In addition, disclosure of personally identifiable information is permitted if necessary for the "routine use" of the receiving facility, a very broad exception.

Finally, the Americans With Disabilities Act (ADA) of 1990 requires employers to maintain medical information in separate files and on discrete forms. As the ADA is enforced, it may lead to increased protection of the privacy of medical records at the workplace. In relevant part, however, the ADA applies only to people with a disability as defined by the statute, and to actions taken by employers based on an individual's disability. Therefore, the ADA provides only limited confidentiality protection; it does not create a general right to medical privacy within the workplace.

Potential Problems With the Current Legal Framework

There is general consensus that the current legal framework for protecting the confidentiality of health care information is inadequate. There are significant differences among the states in addressing confidentiality issues. While a state-by-state approach may have been good policy before recent trends in the organization and financing of health care, the increasing dominance of the health care industry by providers and payers doing business on a national scale has caused many to advocate for a national confidentiality standard.

This lack of uniformity may be exacerbated in the context of mental health care. There are differences in standards not only among the states, but between the states and the Federal government. Separate state standards for mental health information and Federal standards for alcohol and substance use information may be problematic in an era in which it has become evident that many people with mental illnesses also have substance abuse or alcohol problems. In addition, there are often within the same state a number of statutory provisions that address the confidentiality of mental health information. These may include the state mental health law (which may apply to all mental health information or only information held by state-operated providers), judicial privilege statutes, laws applicable to licensed professionals, and various state oversight laws. This may make it difficult even within a particular state to articulate the state law on the confidentiality of mental health information.

Many state mental health laws also lack provisions that most reform proposals contain. For example, many states do not articulate standards for client consent to disclosure. In contrast, most reform proposals require that consent be in writing, be of definite rather than indefinite duration, and specify recipients of information rather than provide open-ended consent to disclose. Many state laws providing for disclosure of mental health information to payers without client consent were written before the increased demands for information common today. Access by other providers is variable as well. Many states provide for comparatively mild penalties for the breach of confidentiality. In contrast, most reform proposals would considerably strengthen penalties for violating confidentiality protections.

As the debate regarding a national standard proceeds, there are two additional issues of consequence for those considering the confidentiality of mental health information. The first is the question of preemption. Most reform proposals considered by Congress in recent years would establish a national standard that would become the minimum standard for health care information. The standard would preempt (or supercede) any state laws that provided less protection than that in the national standard. The Secretary of the Department of Health and Human Services recommended such an approach in a recent report to Congress entitled, *Confidentiality of Individually Identifiable Health Information*. Should a national standard be enacted, determining whether a state's mental health law provides more or less protection than a national standard may be difficult in at least some cases. For example, in one state, the law permits disclosures without consent to some but not all types of providers. One of the proposals to establish a national standard would permit disclosures to be made to other providers without the consent of the individual, but would give the individual the opportunity to "opt out" of disclosures to specified providers. In this example, it is difficult to determine whether the state law in question is more or less protective than the proposed national standard. On the one hand, the state law in this example is more restrictive than the reform proposal because it limits the types of providers that can receive information without consent. On the other hand, it is weaker than the reform proposal because it does not provide the individual with an opportunity to decline permission to disclose to those providers. The problem is not insurmountable: in this example, one solution might be to apply the opt-out provision of the national standard to that part of the state law that permits some types of disclosures without consent. At the same time, the current condition of many state mental health laws may make application of the preemption principle difficult.

A second important question is whether there should continue to be separate legal standards for mental health confidentiality and for substance use and alcohol use confidentiality. The reform proposals advanced to date generally would leave the Federal substance use law intact. This would have the practical effect of locking in the disparate standards that currently exist for mental health information (governed by state laws) and substance and alcohol use information (governed by the Federal law). Some experts disagree with the notion of having discrete, disease-based standards, on the ground that there are other diseases that raise legitimate concerns regarding privacy that do not receive special protection (Gostin, 1995). Others would retain the strict protections currently available to substance and alcohol use data, while extending the same protections to mental health information. This report does not endorse either perspective. However, it would be useful to examine more closely whether disparate standards have an effect on clinical practice and on the privacy expectations of individuals in treatment, particularly those with both a mental illness and a substance abuse diagnosis.

Summary

There are many reasons why an individual with a mental illness might decide not to seek treatment. For example, some people might forego treatment for financial reasons. Others might decide that the risk of stigma and discrimination that people with mental illness still encounter is too high a price to bear. In the latter situation, being able to provide assurances that the principle of confidentiality receives strong protection may make the difference in the decision to enter and participate fully in treatment.

Confidentiality is a matter of both ethical and legal concern. As noted earlier, each of the health care professions endorses confidentiality as a core matter. However, it is the law that establishes the basic rules that govern confidentiality in practice. The law can expand confidentiality, as the U.S. Supreme Court did when it ruled that a psychotherapeutic privilege would apply in Federal court. The law also can decide that the principle of confidentiality must yield to other values, as the California Supreme Court did when it decided that mental health professionals had an obligation to protect third parties whom the professional reasonably concluded could be endangered by a client in treatment.

It is clear that confidentiality is not absolute. There are other competing values that require its breach in certain circumstances. However, it also seems clear that there are significant gaps in the current legal framework that protects the confidentiality of mental health information. Consideration of an appropriate level of legal protection for mental health information should acknowledge that mental illness continues to be a category of illness that may subject a person receiving a diagnosis to discrimination and other disadvantages.

In the absence of strong confidentiality protections, some individuals with mental illness may decide that the benefit of treatment is outweighed by the risk of public disclosure. This would be harmful not only to the individual, but to a public that has a stake in the mental health of its members. The U.S. Supreme Court summarized this public interest succinctly in the decision quoted at the beginning of this section:

> *The psychotherapist privilege serves the public interest by facilitating the provision of appropriate treatment for individuals suffering the effects of a mental or emotional problem. The mental health of our citizenry, no less than its physical health, is a public good of transcendent importance.* (Jaffee v. Redmond, 1996)

It is to be hoped that this public good, as well as the private good represented by successful treatment for mental illness, governs the continuing debate regarding the protection of confidentiality.

Conclusions

In an era in which the confidentiality of all health care information, its accessibility, and its uses are of concern to all Americans, privacy issues are particularly keenly felt in the mental health field. An assurance of confidentiality is understandably critical in individual decisions to seek mental health treatment. Although an extensive legal framework governs confidentiality of consumer-provider interactions, potential problems exist and loom ever larger.

1. People's willingness to seek help is contingent on their confidence that personal revelations of mental distress will not be disclosed without their consent.
2. The U.S. Supreme Court recently has upheld the right to the privacy of these records and the therapist-client relationship.
3. Although confidentiality issues are common to health care in general, there are special concerns for mental health care and mental health care records because of the extremely personal nature of the material shared in treatment.
4. State and Federal laws protect the confidentiality of health care information but are often incomplete because of numerous exceptions which often vary from state to state. Several states have implemented or proposed models for protecting privacy that may serve as a guide to others.
5. States, consumers, and family advocates take differing positions on disclosure of mental health information without consent to family caregivers. In states that allow such disclosure, information provided is usually limited to diagnosis, prognosis, and information regarding treatment, specifically medication.
6. When conducting mental health research, it is in the interest of both the researcher and the individual participant to address informed consent and to obtain certificates of confidentiality before proceeding. Federal regulations require informed consent for research being conducted with Federal funds.
7. New approaches to managing care and information technology threaten to further erode the confidentiality and trust deemed so essential between the direct provider of mental health services and the individual receiving those services. It is important to monitor advances so that confidentiality of records is enhanced, instead of impinged upon, by technology.
8. Until the stigma associated with mental illnesses is addressed, confidentiality of mental health information will continue to be a critical point of concern for payers, providers, and consumers.

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CHAPTER 8

A VISION FOR THE FUTURE

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CHAPTER 8

A VISION FOR THE FUTURE

Mental health is fundamental to health and human functioning. Yet much more is known about mental illness than about mental health. Mental illnesses are real health conditions that are characterized by alterations in thinking, mood, or behavior—all mental, behavioral, and psychological symptoms mediated by the brain. Mental illnesses exact a staggering toll on millions of individuals, as well as on their families and communities and our Nation as a whole. Appropriate treatment can alleviate, if not cure, the symptoms and associated disability of mental illness. With proper treatment, the majority of people with mental illness can return to productive and engaging lives. There is no "one size fits all" treatment; rather, people can choose the type of treatment that best suits them from the diverse forms of treatment that exist.

The main findings of the report, gleaned from an exhaustive review of research, are that the efficacy of mental health treatments is well documented and a range of treatments exists for most mental disorders. On the strength of these findings, the single, explicit recommendation of the report is to seek help if you have a mental health problem or think you have symptoms of a mental disorder.

Today, the *majority* of those who need mental health treatment do not seek it. The reluctance of Americans to seek and obtain care for mental illness is all too understandable, given the many barriers that stand in their way. If the information contained in this Surgeon General's report is to be translated into its recommended action—*to seek help for mental illness*—our society must resolve to dismantle barriers to seeking help that are sizable and significant, but not insurmountable.

This vision for the future proposes to the American people broad courses of action meant to hasten progress toward the major recommendation of this report. These calls to action constitute necessary first steps toward overcoming the gaps in what is known and removing the barriers that keep people from seeking and obtaining mental health treatment. Although these are not formal policy recommendations, they offer a focused vision that may inform future policy. They are intended for policymakers, service and treatment providers, professional and advocacy organizations, researchers, and, most importantly, the American people. The health of the American people demands that we act with resolve and a sense of urgency to place mental health as a cornerstone of health and address through research and education both the impact and the stigma attached to mental illness.

Continue To Build the Science Base

The Nation has realized immense dividends from 5 decades of investment in research focused on mental illness and mental health. Yet to realize further advances in treatment and, ultimately, prevention, the Nation must continue to invest in research at all levels. This Surgeon General's report is issued at a time of unprecedented scientific opportunity. Today, integrative neuroscience and molecular genetics present some of the most exciting basic research opportunities in medical science. Molecular and genetic tools are being used to identify genes and proteins that might be involved in the origins of mental illness and that clearly are altered by drug treatment and by the environment. Genes and gene products promise to provide novel targets for new medications and psychosocial interventions. The opportunities available underscore the need for the Federal mental health research community to strengthen partnerships with both the biotechnology and the pharmaceutical industries. Gaining new knowledge about mental illness and health is everybody's business. A plethora of new pharmacologic agents and psychotherapies for mental disorders affords new treatment opportunities but also challenges the scientific community to develop new approaches to clinical and health services interventions research. Responding to the calls of managed mental and behavioral health care systems for evidence-based interventions will have a much needed and discernible impact on practice. Also, as this Surgeon General's report emphasizes, high-quality research is a potent weapon against stigma, one that forces skeptics to let go of misconceptions and stereotypes concerning mental illness and the burdens experienced by persons who have these disorders.

Special effort is required to address pronounced gaps in the mental health knowledge base. Key among these are the urgent need for research evidence that supports strategies for mental health promotion and illness prevention. Each chapter in this report has identified additional, specific gaps that must be addressed.

The vitality of clinical research hinges on the willing participation of clinical research volunteers. By law, subjects in federally sponsored research are required to give informed consent—that is, to agree to participate voluntarily after being informed about the purpose, benefits, and risks of the research, among other requirements (45 CFR 46). The law affords special protections for children and for persons with impaired decisionmaking capacity. Policies must be promulgated to ensure that vulnerable individuals are protected while they participate in research needed for the development of new treatments.

Overcome Stigma

The stigma that envelops mental illness deters people from seeking treatment. Stigma assumes many forms, both subtle and overt. It appears as prejudice and discrimination, fear, distrust, and stereotyping. It prompts many people to avoid working, socializing, and living with people who have a mental disorder. Stigma impedes people from seeking help for fear that the confidentiality of their diagnosis or treatment will be breached. It gives insurers—in the public sector as well as the private—tacit permission to restrict coverage for mental health services in ways that would not be tolerated for other illnesses. Chapter 1 reviewed the influence of stigma historically in separating mental health from the mainstream of health and its role in thwarting access to appropriate treatment. Powerful and pervasive, stigma prevents people from acknowledging their own mental health problems, much less disclosing them to others.

For our Nation to reduce the burden of mental illness, to improve access to care, and to achieve urgently needed knowledge about the brain, mind, and behavior, stigma must no longer be tolerated. The issuance of this Surgeon General's Report on Mental Health seeks to help reduce stigma by dispelling myths about mental illness and by providing accurate knowledge to ensure more informed consumers. Organizations and individuals are encouraged to draw freely upon the report in their own efforts to combat the insidious effects of stigma.

Improve Public Awareness of Effective Treatment

The Surgeon General's report itself is expected to stimulate the demand for effective treatment for needed mental health care. Americans are often unaware of the choices they have for effective mental health treatments. In fact, as the preceding chapters demonstrate, there exists a constellation of treatments for most mental disorders. Treatments fall mainly under several broad categories—counseling, psychotherapy, medication therapy, rehabilitation—yet within each category are many more choices.

Individuals should be encouraged to seek help from any source in which they have confidence. If they do not improve with the help obtained initially, they should be encouraged to keep trying to obtain assistance. If the path of help-seeking leads to only limited improvement, an array of options still exists: the intensity of treatment may be changed, new treatments may be introduced, or another provider may be sought.

Family members, clergy, and friends often can help by encouraging a distressed person to seek help.

All human services professionals, not just health professionals, have an obligation to be better informed about mental health treatment resources in their communities. Managed care companies and other health insurers need to publish clear information about their mental health benefits (usually called "behavioral health benefits"). At present, many beneficiaries appear not to know *if* they have mental health coverage, much less where to seek help for problems.

Ensure the Supply of Mental Health Services and Providers

The service system as a whole, as opposed to treatment services considered in isolation, dictates the outcome of treatment (Goldman, 1998). The fundamental components of effective service delivery include integrated community-based services, continuity of providers and treatments, family support services (including psychoeducation), and culturally sensitive services. Effective service delivery for individuals with the most severe conditions also requires supported housing and supported employment. For adults and children with less severe conditions, primary health care, the schools, and other human services must be prepared to assess and, at times, to treat individuals who come seeking help. All services for those with a mental disorder should be consumer oriented and focused on promoting recovery. That is, the goal of services must not be limited to symptom reduction but should strive for restoration of a meaningful and productive life.

Across the Nation, certain mental health services are in consistently short supply. These include the following:

- Wraparound services for children with serious emotional problems and multisystemic treatment. Both treatment strategies should actively involve the participation of the multiple health, social service, educational, and other community resources that play a role in ensuring the health and well-being of children and their families;
- Assertive community treatment, an intensive approach to treating people with serious mental illnesses;
- Combined services for people with co-occurring severe mental disorders and substance abuse disorders;
- A range of prevention and early case identification programs; and
- Disease management programs for conditions such as late-life depression in primary care settings.

All too frequently, these effective programs are simply unavailable in communities. It is essential to expand the supply of effective, evidence-based services throughout the Nation.

The supply of well-trained mental health professionals also is inadequate in many areas of the country, especially in rural areas (Peterson et al., 1998). Particularly keen shortages are found in the numbers of mental health professionals serving children and adolescents with serious mental disorders and older people (Peterson et al., 1998). More mental health professionals also need to be trained in cognitive-behavioral therapy and interpersonal therapy, two forms of psychotherapy shown by rigorous research to be effective for many types of mental disorders.

Ensure Delivery of State-of-the-Art Treatments

State-of-the-art treatments, carefully refined through years of research, are not being translated into community settings. As noted throughout this report, a wide variety of community-based services are of proven value for even the most severe mental illnesses. Exciting new research-based advances are emerging that will enhance the delivery of treatments and services in areas crucial to consumers and families—employment, housing, and diversion of people with mental disorders out of the criminal justice systems. Yet a gap persists in the broad introduction and application of these advances in services delivery to local communities, and many people with mental illness are being denied the most up-to-date and advanced forms of treatment.

Multiple and complex explanations exist for the gap between what is known through research and what is actually practiced in customary care. Foremost among these are practitioners' lack of knowledge of research results; the lag time between the reporting of research results and the translation of new knowledge into practice; and the cost of introducing innovations in health systems. In addition, significant differences that exist between academic research settings and actual practice settings help account for the gap between what is known and what is practiced. The patients in actual practice are more heterogeneous in terms of their overall health and cultural backgrounds, and both patients and providers are subject to cost pressures. New strategies must be devised to bridge the gap between research and practice (National Advisory Mental Health Council, 1998).

Tailor Treatment to Age, Gender, Race, and Culture

This report presents clear evidence that mental health and mental illness are shaped by age, gender, race, and culture as well as additional facets of diversity that can be found within all of these population groups—for example, physical disability or a person's sexual orientation. The consequences of not understanding these influences can be profoundly deleterious.

To be effective, the diagnosis and treatment of mental illness must be tailored to individual circumstances, while taking into account, age, gender, race, and culture and other characteristics that shape a person's image and identity. Services that take these demographic factors into consideration have the greatest chance of engaging people in treatment, keeping them in treatment, and helping them to recover thereafter. The successful experiences of individual patients will positively influence attitudes toward mental health services and service providers, thus encouraging others who may share similar concerns or interests to seek help.

While women and men experience mental disorders at almost equal rates, some mental disorders such as depression, panic disorder, and eating disorders affect women disproportionately. The mental health service system should be tailored to focus on women's unique needs (Blumenthal, 1994).

Members of racial and ethnic minority groups account for an increasing proportion of the Nation's population. Mental illness is at least as prevalent among racial and ethnic minorities as in the majority white population (Regier et al., 1993). Yet many racial and ethnic minority group members find the organized mental health system to be uninformed about cultural context and, thus, unresponsive and/or irrelevant. It is partly for this reason that minority group members overall are less inclined than whites to seek treatment (Sussman et al., 1987; Gallo et al., 1995), and to use outpatient treatment services to a much lesser extent than do non-Hispanic whites. Yet it is important to acknowledge and appreciate that there exist wide variations within and among racial and ethnic minority groups with respect to use of mental health services. The use of inpatient treatment services by African Americans, for example, is much higher than use of these services by whites, a difference that cannot be accounted for by differences in prevalence alone (Chapter 2). The reasons for these disparities in utilization of services must be further understood through research. In the interim, culturally competent services—that is, services that incorporate understanding of racial and ethnic groups, their histories, traditions, beliefs, and value systems—are needed to enhance the appropriate use of services and effectiveness of treatments for ethnic and racial minority consumers. With appropriate training and a fundamental respect for clients, any mental health professional can provide culturally competent services that reflect sensitivity to individual differences and, at the same time, assign validity to an individual's group identity. Still, many members of ethnic and racial minority groups may prefer to be treated by mental health professionals of similar background. There is an insufficient number of mental health professionals from racial and ethnic minority groups (Peterson et al., 1998), a problem that needs to be corrected.

Facilitate Entry Into Treatment

The mental health service system is highly fragmented. Many who seek treatment are bewildered by the maze of paths into treatment; others in need of care are stymied by a lack of information about where to seek effective and affordable services. In recent years, some progress has been made in coordinating services for those with severe mental illness, but more can be accomplished. Public and private agencies have an obligation to facilitate entry into treatment. There are multiple "portals of entry" to mental health care and treatment, including a range of community and faith-based organizations. Primary health care could be an important portal of entry for children and adults of all ages with mental disorders. The schools and child welfare system are the initial points of contact for most children and adolescents, and can be useful sources of first-line assessment and referral, provided that expertise is available. The juvenile justice system represents another pathway, although many overburdened facilities tend to lack the staff required to deal with the magnitude of the mental health problems encountered. Of equal concern are the adult criminal justice and corrections systems, which encounter substantial numbers of detainees with mental illness (Ditton, 1999). Individuals with mental disorders often are neglected or victimized in these institutions.

It is essential for first-line contacts in the community to recognize mental illness and mental health problems, to respond sensitively, to know what resources exist, and to make proper referrals and/or to address problems effectively themselves. For the general public, primary care represents a prime opportunity to obtain mental health treatment or an appropriate referral. Yet primary health care providers vary in their capacity to recognize and manage mental health problems. Many highly committed primary care providers do not know referral sources or do not have the time to help their patients find services.

Some people do not seek treatment because they are fearful of being forced to accept treatments not of their choice or of being treated involuntarily for prolonged periods (Sussman et al., 1987; Monahan et al., 1999). For most, these fears are unwarranted: coercion, or involuntary treatment, is restricted by law only to those who pose a direct threat of danger to themselves or others or, in some instances, who demonstrate a grave disability. Coercion takes the form of involuntary commitment to a hospital; in about 40 states and territories, it includes certain outpatient treatment requirements. Advocates for people with mental illness hold divergent views regarding coercion. Some advocates crusade for more stringent controls and treatment mandates, whereas others adamantly oppose coercion on any grounds. One point is clear: the *need* for coercion should be reduced significantly when adequate services are readily accessible to individuals with severe mental disorders who pose a threat of danger to themselves or others (Policy Research Associates, 1998). As the debate continues, more study is needed concerning the effectiveness of different strategies to enhance compliance with treatment. Almost all agree that coercion should not be a substitute for effective care that is sought voluntarily.

Reduce Financial Barriers to Treatment

Financial obstacles discourage people from seeking treatment and from staying in treatment. Repeated surveys have shown that concerns about the cost of care are among the foremost reasons why people do not seek care (Sussman et al., 1987; Sturm & Sherbourne, 1999). As documented in Chapter 6 of this report, there is an enormous disparity in insurance coverage for mental disorders in contrast to other illnesses. Mental health coverage often is arbitrarily restricted. Individuals and families consequently are forced to draw on relatively—and substantially—more of their own resources to pay for mental health treatment than they pay for other types of health care. This inequity is a deterrent to treatment and needs to be redressed.

Recent legislative efforts to mandate equitable insurance coverage for mental health services have been heralded as steps in the right direction for reducing financial barriers to treatment. Still, for the more than 44 million Americans who lack *any* health insurance, equity of mental health and other health benefits is moot. For many who do have health insurance, coverage restrictions for mental health treatment persist. Data reveal that access to and use of services have increased following enhancements of mental health benefits in private insurance, Medicare, Medicaid, and the Federal Employees Health Benefit Program. Chapter 6 of this report makes it clear that equality between mental health coverage and other health coverage—a concept known as "parity"—is an affordable and effective objective. In states in which legislation requires parity of mental health and general coverage, cost increases are nearly imperceptible as long as the care is managed. A recent paper suggests that the value of mental health treatment has increased in recent years—that is, effectiveness has increased—while expenditures have fallen (Frank et al., 1999). In light of cost-containment strategies of managed care, concerns about undertreatment still are warranted for individuals with the most severe mental disorders, but high-quality managed care has the potential to effectively match services to patient needs.

Conclusion

This Surgeon General's Report on Mental Health celebrates the scientific advances in a field once shrouded in mystery. These advances have yielded unparalleled understanding of mental illness and the services needed for prevention, treatment, and rehabilitation. This final chapter is not an endpoint but a point of departure. The journey ahead must firmly establish mental health as a cornerstone of health; place mental illness treatment in the mainstream of health care services; and ensure consumers of mental health services access to respectful, evidenced-based, and reimbursable care.

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